

Counting for Something

How New Zealand agencies record, investigate,
and review deaths of people with intellectual
disability



*"For those we knew, and those
unknown, they shall not be forgotten".*

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27 October 2020

Suggested Citation:

Brandford S. 2020 "Counting for Something – How New Zealand agencies record, investigate and review deaths of people with intellectual disability". Wellington, New Zealand

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ACKNOWLEDGEMENTS

I received funding from the IHC Foundation to undertake this project, to write a report for public dissemination, and to host a discussion based on my findings. I am grateful to the Foundation for enabling me to conduct a project with this wide scope, and for tolerating delays in its completion.

While this report has been prepared by one person, it reflects the contributions and insights of many individuals and agencies. I interviewed a number of dedicated and learned people whose comments have informed and greatly enriched this report.

I acknowledge the thoughtful approach everyone has taken to my queries, and welcomed all insights. My findings have been peer reviewed by the Donald Beasley Institute, and their critique has strengthened this final report.

The report and all its findings are the sole authorship of me, Sharon Brandford. Any errors in interpretation are unintentional, and I trust they can be resolved through dialogue and future collaboration.

EXECUTIVE SUMMARY

Governments seek good health outcomes for their citizens and residents. New Zealand's Health Strategy 2020 sets a vision that "All New Zealanders live well, stay well and get well". One of the main ways governments and health professionals address health inequities that lead to death is through investigation and reviews of deaths of similar groups.

I am an independent disability consultant. I became motivated to understand better how we apply this public health approach to people with intellectual disability who experience poorer health outcomes and high rates of unmet health needs, which can have a profound effect on mortality. They die much younger than the general population as a result of multiple and complex health needs, which are often unrecognised or poorly managed.

Funding for this research was awarded by a philanthropic trust, the IHC Foundation. The specific aim of the project was to explore and describe how deaths of children and adults with intellectual disability are recorded, reported, investigated, and reviewed in New Zealand. The purpose of the work was to encourage and inform a sustained focus on improving health and longevity given the paucity of such research in New Zealand.

Information was gathered from statutory and non-government agencies. This included the Coroners Court, the Office of the Health and Disability Commissioner, the Ministry of Health (its Disability Directorate and its Mortality Collection team), the Health Quality Safety Commission's Child and Youth Mortality Review Committee, and a number of community disability providers. I read relevant legislation and commentaries about legislation currently under review. Document analysis was also undertaken through reading relevant annual reports as well as a selection of Coroners' reports where it was likely the subject had an intellectual disability.

In 2011, the Ministry of Health published significant work specific to people with intellectual disability using health utilisation data. That report found that people with intellectual disability had a life expectancy 18-23 years less than the general population, were more likely to receive care or treatment for chronic health conditions, were more likely to use primary health services, were dispensed twice as many types of prescription drugs, and were four times as likely to have had avoidable hospital admissions.

However it is difficult to obtain robust information about the implications of this utilization data on mortality. Few New Zealand agencies can easily extract disability-specific information from their death-related data collections or reports. Variable definitions of intellectual disability limit the usability of data from several different sources. New Zealand death review work has focussed only on people who died in residential care, and only a small subset of residents had their deaths scrutinised. Focusing on only those in residential care ignores a large group who rely on others for their well-being, and for treatment when they become unwell. Overseas research applies broader criteria for inclusion in mortality review processes. This widens the lens from just focussing on quality of care provision to also include the quality of the health services provided.

Efforts to improve health outcomes particular to people with disabilities appear to be piecemeal and faltering, with little clear strategy. Till very recently, there has been little progress on longstanding government commitments to disaggregate disability in survey and administrative data. The impact of this on understanding mortality of people with intellectual disability is significant. For example, we do not know how many people there are with intellectual disability in New Zealand, and it is difficult to know how many die annually.

The Chief Ombudsman's investigation of the Ministry of Health's role in understanding and responding to reported deaths of people in care described a poor current response, and this has been described by Julian's 2020 observations of New Zealand's response as apathetic compared with overseas jurisdictions. Acting on the Chief Ombudsman's recommendations will strengthen our national response to the poor health outcomes and life expectancy of people with intellectual disability.

All agencies involved in recording, investigating and reviewing deaths in New Zealand were committed to reducing preventable deaths. However, it was not easy to see how lessons identified by one were shared across work streams. None had undertaken targeted reviews specific to the people of concern in this report. Three have the legal mandate to do so.

This scoping project has identified that there are considerable challenges ahead to get and use meaningful data. However, there is substantial overseas research applicable to New Zealand. This could be used as a basis for strengthening / improving our current system. It is further recommended that this work be led by an independent body. With cross-agency collaboration, mutually relevant learnings can be identified and shared while we improve the systems and cycles for collecting administrative data. Within this report I have suggested potential ways forward, as the basis for further discussion.

This report touches on preconceptions about quality of life that family, friends, and caregivers commonly hear when health concerns arise. Unconscious bias about the value of people's lives and inevitability of early death is reported overseas, and within New Zealand by some families. If we are to increase the visibility of people with intellectual disability in health and mortality research we must also challenge such attitudes. Advocacy and human rights groups can contribute to this work.

New Zealand has a robust system for accurately recording, investigating and reviewing deaths of New Zealanders. This robust system should also be applied to the deaths of New Zealanders with intellectual disability to ensure their deaths counted for something. This needs to be done with urgency.

Glossary

| | |
|-------------------------|---|
| ACC | Accident Compensation Corporation |
| AELP | Adverse Events Learning Programme |
| Coroners Court | Coronial Services of New Zealand - https://coronialservices.justice.govt.nz |
| CYMRC | Child and Youth Mortality Review Committee |
| DDEWG | Disability Data and Evidence Working Group (coleadership by Office for Disability Issues and Stats New Zealand) |
| DD | Disability Directorate of Ministry of Health (formerly called Disability Support Services) |
| DHB | District Health Boards |
| DNR | Do Not Resuscitate order |
| HDC | Office of the Health and Disability Commissioner Health and Disability Commissioner - https://www.hdc.org.nz/ |
| HQSC | Health Quality & Safety Commission New Zealand - https://www.hqsc.govt.nz |
| ICD-10 | International Statistical Classification of Diseases (version 10) |
| IDI | Integrated Data Infrastructure |
| IDCCR Act | Intellectual Disability Compulsory Care and Rehabilitation Act 2003 |
| LeDeR | Learning Disability Mortality Review Programme (UK) |
| MCCD | Medical Certificate of Cause of Death |
| MORT | Ministry of Health – Mortality Collection Team |
| NDIS | National Disability Insurance Scheme (Australia) |
| NZDSN | New Zealand Disability Support Network |
| Office of the Ombudsman | https://www.ombudsman.parliament.nz/about |
| Oranga Tamariki | Ministry for Children, formerly Child, Youth and Family Services |
| RIDSAS | Regional Intellectual Disability Supported Accommodation Services |
| RIDSS | Regional Intellectual Disability Secure Services |
| UNCRPD | the United Nations Convention on the Rights of Persons with Disabilities |

1. BACKGROUND

In rural Waikato, on a hill facing an ‘empty’ paddock is a black granite memorial wall. It commemorates the 457 people buried there – some of the deceased residents of the former Tokanui Psychiatric Hospital. Many of them were people with intellectual disability. Some graves are unmarked.

Engraved on the memorial’s face are the names of those who – according to the hospital’s records list – are interred in what had been the hospital’s cemetery, now a paddock. Also engraved is a quote, *“For those we knew, and those unknown, they shall not be forgotten”*.



Family members established a Trust¹ that resulted in this memorial and related restoration work. They were troubled by the invisibility of their deceased family members. Combined with the efforts of others, they have restored greater dignity for lost family members and raised our awareness of lives lived apart from wider society. Their concerns echoed those from bereaved families elsewhere.

This project was undertaken to provide a baseline record of how New Zealand currently records and investigates the deaths of people with intellectual disability. I wanted to find out how we could use the knowledge we currently have about deaths to improve the poor health outcomes for New Zealanders with intellectual disability.

Several pending changes make this report timely, and may heighten the need for closer attention to this issue. The government is implementing substantial reform of the role of Ministry of Health in disability supports, a move which will see people with disability supported by frameworks that may be outside existing quality assurance and reporting mechanisms. It is unclear at this point whether the reforms will make it easier to monitor unexpected or premature deaths. A high-level review of health and disability systems has also been released², signalling potential changes for the relationship between our health and disability sectors.

On October 17th 2020, the country voted in a referendum to enact legislation enabling assisted end-of-life measures, under a backdrop of expressed concerns about the impact on vulnerable populations. The results of this and its implications are yet to be determined. At the same time, changes in mandatory reporting of sentinel events and their subsequent public scrutiny have resulted in a climate of naming and shaming, which may be counterproductive to the open sharing of knowledge about how and why deaths have occurred.

Two directly related documents were released during the period of this scoping project.

The first was the Chief Ombudsman’s report ‘Off the Record: An investigation into the Ministry of Health’s collection, use, and reporting of information about the deaths of people with intellectual disabilities’.³ The investigation focused on deaths of people who resided in District Health Board and non-government community facilities. The report was published in July 2020. It is based on a sample of 108 from 267 deaths reported to the Ministry of Health across a 2.5 year period.⁴ The Chief

¹ Tokanui Hospital Cemetery Restoration Project. <https://tokanuihospitalcemetery.weebly.com>

² ‘Health and Disability System Review – Final Report – Pūrongo Whakamutunga’. Wellington: HDSR, 2020

³ ‘Off the Record: An investigation into the Ministry of Health’s collection, use, and reporting of information about the deaths of people with intellectual disabilities.’

<https://www.ombudsman.parliament.nz/resources/off-the-record>.

⁴ It appears the Ministry of Health had no record of a further 35 deaths within the sample regions.

Ombudsman found that the Ministry had neither conducted nor commissioned reviews of deaths, despite its own earlier research indicating poor health outcomes for intellectually disabled New Zealanders. The Chief Ombudsman made operational and strategic recommendations to the Ministry of Health.

This was the first such report by a statutory body in New Zealand on this matter, and is highly relevant to the current report and therefore is referred to throughout. This scoping report differs from the Chief Ombudsman's report in two major respects:

- It considers children and adults with intellectual disabilities supported by others in a wider range of living arrangements, not just those in residential care; and
- It considers the role of other significant agencies involved in mortality reviews and investigation of deaths, rather than focussing solely on the Ministry of Health's administrative functions.

The second document released was a report by Dr George Julian, a disability activist from the United Kingdom.⁵ She completed a Winston Churchill Fellowship study comparing the approach to death investigations in Australia, Canada, and New Zealand, with a focus on families' experiences. Dr Julian's report was released in August 2020. After visiting New Zealand, Julian was of the opinion that New Zealand demonstrated "the most acute sense of apathy" about addressing poor health outcomes and premature deaths of people with intellectual disability.⁶

At this project's start, I was familiar with overseas disability-specific literature about health and risks of premature death. But there was a data vacuum regarding New Zealand's situation. The report describes what current and potential sources of information could be used to support sustained research here.

Method

Before formally undertaking this project, preliminary consultation occurred with a small number of people and agencies. This included senior Disability Directorate officials from the ministry of Health, the Donald Beasley Institute, and the Chief Coroner, who all endorsed the need for this topic to be explored. Advice was also sought in relation to the method used in this scoping project from two key researchers in this field - Dr Brigit Mirfin-Veitch, Director of the Donald Beasley Institute in New Zealand, and Professor Pauline Heslop, the lead investigator of the Learning Disability Mortality Review (LeDeR) Programme⁷ at the University of Bristol in England. This preliminary guidance was most helpful.

In May 2018, I applied for funding from the IHC Foundation⁸ to undertake a scoping project. The Foundation accepted my proposal, and subsequently recommended I include the findings of the investigation by the Chief Ombudsman announced in February 2019.

Once funding was approved, I explored what material was publicly available on the roles of agencies involved in collecting, analysing and disseminating information about deaths in New Zealand. This included reading legislation, annual and occasional reports, and accessing material on websites. I also

⁵ Walking backwards into the future: involving families in investigating the deaths of learning disabled people. Dr George Julian (2020) <http://www.georgejulian.co.uk/churchill/>

⁶ See footnote 5, p36.

⁷ <http://www.bristol.ac.uk/sps/leder/>

⁸ The IHC Foundation is a charitable trust that raises and grants funds to a range of projects that benefit people with intellectual disability and their families.

selected and analysed published literature from here and overseas about health outcomes and mortality reviews.

I identified common questions to put to agencies – about their statutory roles, limits to those roles, as well as their awareness and experience specific to the subjects of this report. Information was gathered through face to face, video meeting or written responses. I was interested to learn how these agencies collect and store their findings and the degree to which people with intellectual disability were identifiable from them. I wanted to understand how the different components of mortality research knitted together. I sought information about who they shared their findings with and the mechanism for this.

I consulted agencies through 2019. I compared the information from these interviews with international research findings to gauge the challenges and opportunities for New Zealand to improve matters. To ensure I could use information from the Ombudsman’s report, my own work was also delayed, and completed in October 2020. Before releasing my report, I sought peer review from the Donald Beasley Institute.

The resulting report details these findings, and includes my opinion on possible ways to promote further dialogue and agreement on work that will make a positive difference.

Information sources

This report includes information on legal and procedural pathways currently available for reporting and investigation of a death.

I identified and sought input from the following agencies and individuals working on mortality matters in New Zealand:

- Office of Chief Coroner: officials and staff from the Coronial Information Service (no Coroners)
- Health and Disability Commissioner (HDC)
- Ministry of Health, Mortality Collection (MORT)
- Ministry of Health, Disability Directorate
- Personnel involved with the Child and Youth Mortality Review Committee (CYMRC) overseen by the Health Quality Safety Commission
- Disability service provider representation: individual disability providers and the Chief Executive from the New Zealand Disability Support Network (NZDSN)
- A Medical Referee
- I requested contact with the Royal NZ College of General Practitioners, but received no response.

Soon after the start of this project, the Chief Ombudsman announced an investigation into how the Ministry of Health collected and used records of deaths of people with intellectual disability in residential care. Accordingly, I notified his office of my work. I indicated to the Disability Directorate that I would use the Ombudsman’s findings rather than duplicate enquiries with them. Prior to completing this report in September 2020, a follow up meeting with Disability Directorate officials provided updates on relevant work programmes underway.

Several individuals provided guidance to broaden my awareness of the complexities of this project. This came from those with specialised knowledge about the mortality of people with intellectual disability, or from families with lived experience of unexplained death. They included:

- Professor Nick Lennox, former Director of the Queensland Centre for Intellectual and Developmental Disability at the University of Queensland, primary health physician, and contributor to Queensland (for guidance on best practice regarding death certification and disability, and impact of Reviews)
- Sam Murray, member of Disability Data and Evidence Working Group (for advice on New Zealand's database development particular to people with disabilities)
- Dr George Julian, British disability activist (Winston Churchill Fellow 2017)
- Shelley Payne, parent (for experience of the processes and reflections from families when unexplained death occurs) plus several parents and siblings who rely on health and disability services for the wellbeing of family members with intellectual disability.

Who am I?

I am a disability professional who has worked for more than 30 years alongside people with intellectual disability and their families. I have held clinical advisory and leadership roles in community-based disability services (IHC, IDEA Services, Timata Hou Inc.) and evaluated community disability services (Standards and Monitoring Services). I look to evidence-based sources to guide my work, and complement this with the evidence of those living with disabilities and their families. In my professional roles I have witnessed the challenges disability staff and health personnel face identifying that a person is unwell, and knowing how and where to get the right treatment in a timely fashion.

A strong motivation for this report was my concern about the invisibility of the lives and deaths of many people with intellectual disability I have known. It troubled me that there was a sense that premature deaths are inevitable, despite knowing that many contributing factors are highly amenable to change.

While in a clinical role in IDEA Services, I led a project to better support elders with intellectual disability. Through that work, I observed a reticence to talk about death, to enquire, and to share lessons from deaths. I commissioned research on how disability support workers and families dealt with the pending death of people they cared about and cared for.⁹ I reported deaths to the Ministry of Health as per contractual requirements in my capacity as a service clinical leader. I investigated deaths that providers or external statutory agencies were concerned about. More recently, I have sharpened my focus on to how we support people to live well and die well.

These experiences led me to enquire what mechanisms and information we have within New Zealand now that we could harness to increase awareness of the poor health and longevity of New Zealanders with intellectual disability, and mobilise to address this.

2. OVERVIEW OF REPORT

Who is this report about?

The report is about New Zealanders, both children and adults, with intellectual disability who have died. It excludes infant and neonatal deaths. This report considers what we currently collect and learn from scrutiny of deaths of people who lived in range of care situations.

⁹ Bellamy, G., Gott, M., Prebble, K., Boyd, M., Neill, H. (2012) Developing Advanced Care Planning For People with Intellectual Disabilities: a study to inform the work of IDEA services, School of Nursing, Faculty of Medical and Health Sciences: University of Auckland, unpublished report

Purpose

The purpose of this project is to describe how the deaths of persons with intellectual disability are currently reported in health, disability and statutory systems in New Zealand and how these deaths are investigated. I want to lay a foundation for collaborations to improve the health status of people with intellectual disability in New Zealand and reduce their premature death.

Chapter outline

Chapter 3 outlines the current state of mortality research both internationally and in New Zealand, referring to some of the key studies and reports. It highlights the continuing vulnerability of people with intellectual disability to poor health outcomes and significantly lower life expectancy.

Chapter 4 discusses definitions of intellectual disability and what it may mean to be 'in care'. It shows that variable definitions can be applied, contested and become problematic for the purposes of identifying specific groups from aggregated data collections.

Chapter 5 outlines what data is currently available in order to address some of the key questions in my report, in particular the size of the population with intellectual disability, how many within this population die each year, and how we might identify deaths warranting closer attention.

Chapter 6 illustrates the challenges in applying current data sets to estimating how many people with intellectual disability die each year, the scale of this relative to the whole population, and what proportion of them would meet statutory criteria currently for being 'in care'.

Chapter 7 discusses the reporting of deaths and those agencies within the health and disability sector that report deaths.

Chapter 8 discusses the internationally recognised challenges of providing accurate death certificates for people who have died from any number of causes, some of which are impacted by living with an intellectual disability.

Chapters 9 discusses the agencies and processes involved in cases where deaths are considered worthy of investigation. These include providers, the Coroners Court, and the Health and Disability Commissioner. The chapter also looks at inter-agency liaison and the involvement of families.

Chapter 10 discusses death reviews. Reviews are not the same as investigations, as reviews seek patterns across multiple deaths and investigate changes that may prevent deaths within particular cohort groups. The chapter discusses overseas review processes. It illustrates New Zealand's current mortality review work by focussing on the work of the Child and Youth Mortality Review Committee.

Chapter 11 considers how lessons learned from investigations and reviews are shared to promote good health and disability practice, and how best to share guidance with the right people.

Chapter 12 discusses opportunities and options for taking action. Some steps have been initiated overseas. They point to ways forward in New Zealand, but including a wider audience than just health professionals, disability professionals, or statutory agencies.

Chapter 13 identifies limitations arising from the scope and methodology of this project.

Chapter 14 draws the key messages from each chapter to a conclusion.

3. CURRENT HEALTH OUTCOME AND MORTALITY RESEARCH

Health Outcomes

Many people with intellectual disability have multiple and complex health needs, which are often unrecognised or poorly managed. They experience high prevalence of epilepsy, respiratory disease, heart disease, associated physical impairments, sensory impairments, thyroid disorders, and the high sustained use of psychotropic medication.¹⁰ These result in poor health and high rates of unmet health needs, which can have a profound effect on mortality.

For many years, research has noted the high prevalence of avoidable health conditions leading to death among people with intellectual disability.¹¹ England's Confidential Inquiry into Premature Deaths of People with intellectual Disability (CIPOLD) reported a number of treatable conditions listed as causes of death.¹² These included constipation, pressure sores, reflux and regurgitation, pneumonia, and infections.

There is also strong evidence that people with intellectual disability have poorer outcomes when they use health services. Evidence of this comes from a range of sources over many years. England's National Health Service (NHS) was challenged for its institutional discrimination in the 2007 report 'Death by Indifference'. That report identified six key factors:

- People with a learning disability are seen to be a low priority
- Many healthcare professionals do not understand much about learning disability
- Many healthcare professionals do not properly consult and involve the families and carers of people with a learning disability
- Many healthcare professionals do not understand the law around capacity and consent to treatment
- Health professionals rely inappropriately on their estimates of a person's quality of life
- The complaints system within NHS's services is often ineffectual, time-consuming, and inaccessible.

¹⁰ Health-related quality of life in people with intellectual disability who use long-term antipsychotic drugs for challenging behaviour. Ramerman L, Hoekstrab P. J, de Kuyper G. *Research in Developmental Disability* (2018) volume 75, 49-58

Emerson E, Baines S. 2010. *Health Inequalities and People with Learning Disabilities in the UK: 2010*. Improving Health and Lives: Learning Disabilities Observatory.

'The right to health of Australians with intellectual disability' Brolan C. et al, (2011) *Australian Journal of Human Rights*; vol17

Trollor J, Srasuebku P, Xu H and Howlett S (2017) Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data, *BMJ Open* 2017: 7

<https://bmjopen.bmj.com/content/7/2/e013489>

World Health Organization. *World Report on Disability*; World Bank: Geneva, Switzerland, 2011.

¹¹ Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: a population study. *American Journal of Mental Retardation* (1995); vol99; pp595–604.

Durvasala S, Beange H, Baker W. Mortality of people with intellectual disability in northern Sydney. *Journal of Intellectual and Developmental Disability* (2002) vol27; pp255–264.

Lin E, Balogh R, Durbin A, Holder L, Gupta N, Volpe T, Isaacs B, Weiss J and Lunskey Y (2019) Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario, ICES.

<https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities>

¹² Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) Final report. Norah Fry Research Centre (2013).

Similar concerns have been more recently replicated in an Australian study of hospital care for children with disabilities.¹³ It found that health workers make assumptions about the child that affects the care provided, that family presence during hospitalisations is needed to protect against care deficits, and that health workers may need greater awareness of how hospitalisation can impact differently for each individual child.

A persisting worry among families and people with disability is the influence of health professionals' perceptions of quality of life.¹⁴ This has been described elsewhere as 'therapeutic nihilism', an attitude that medical intervention may have little benefit for the person.¹⁵ Professor Nick Lennox, an Australian authority on primary health care for people with intellectual disability, has publicly called for more open dialogue and coordination between health and disability systems to confront therapeutic nihilism. In the box is an illustration of this experienced by parents whose 29-year-old son was admitted to a New Zealand hospital with aspiration pneumonia.

The treating doctor asked me [Mum], "We don't need to do anything, do we?" The doctor enquired about my perceived quality of life [should he survive]. Despite insisting he be treated actively, we found Peter on his back in a darkened side room of the ward, as if waiting for death.

Disability service providers do not necessarily employ health professionals to support their work. The disability workforce therefore is sometimes poorly placed to monitor and assist people who become unwell to get prompt and appropriate treatment. So we must look not only at the conditions in which people with intellectual disability die, but also at the response of the health and disability systems when they present with health concerns. In a recent Australian study of inclusive practices in hospital settings, four elements of good practice were identified.¹⁶ Those elements were providing support to the person with intellectual disability through the hospital journey, providing persons specific information to hospital staff, collaboration between families, hospital and disability personnel, and reciprocal knowledge about the health and disability sectors.

New Zealand research regarding poor health outcomes

In 2011, the Ministry of Health published significant work specific to people with intellectual disability using health utilisation data. The report was called 'Health Indicators for New Zealanders with Intellectual Disability'.¹⁷ It filled a large gap in New Zealand's evidence base regarding the health status of New Zealanders with intellectual disability.

¹³ Mimmo L, Harrison R and Hinchcliff R (2018) Patient safety vulnerabilities for children with intellectual disability in hospital: a systematic review and narrative synthesis, British Medical Journal Pediatrics Open 2018: 2 <https://bmjpaedsopen.bmj.com/content/2/1/e000201>

¹⁴ Appolonia M, Nieuwenhuijse, Dick L, Willems & Erik Olsman (2019): Physicians' perceptions on Quality of Life of persons with profound intellectual and multiple disabilities: A qualitative study, Journal of Intellectual & Developmental Disability, DOI: 10.3109/13668250.2019.1580117

¹⁵ "a kind of belief that because there's not much more you can do as a health provider you don't do it because you don't believe its going to make any difference" Quoted in online media story ABC News 27/7/2019 accessed 22 February 2020. <https://www.abc.net.au/news/2019-09-27/harrison-creevey/11551564?nw=0> Harrison Creevy (Australia). "Disabled teenager dies after flu complications, parent claim medical response inadequate".

¹⁶ Bigby, C., Douglas, J., & Iacono, T. (2018). Enabling mainstream systems to be more inclusive and responsive to people with disabilities: Hospital encounters of adults with cognitive disabilities. Report for the National Disability Research and Development Agenda. Melbourne: Living with Disability Research Centre, La Trobe University. <http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository/latrobe:42635>

¹⁷ Health Indicators for New Zealanders with Intellectual Disability. 2011. Wellington: Ministry of Health.

The Health Indicators report noted poorer health for New Zealanders with intellectual disability on a number of measures compared with those without intellectual disability. In particular New Zealanders with intellectual disability:

- had significantly lower life expectancy: 18 years less (for males) and 23 years less (for females) than for all New Zealanders (compared with differentials of 6.8 years and 7.3 years for Māori men and Māori women respectively)¹⁸
- were more likely to receive care or treatment for chronic health conditions
- were more likely to use primary health services
- were dispensed twice as many types of prescription drugs, and
- were four times as likely to have had avoidable hospital admissions.

Chronic health conditions featured significantly in that study sample. New Zealanders with intellectual disability were 30 times more likely to be identified as having epilepsy than people without intellectual disability (p28). Their rate of care or treatment for chronic health conditions was approximately 1.5 times higher than the rate for the rest of the New Zealand population. Almost a third of the people with intellectual disability (31.5%) received some form of care or treatment for one or more of six major health conditions (coronary heart disease, chronic respiratory disease, diabetes, chronic kidney disease, cancer, morbid obesity).

The report was intended as a baseline from which to measure effects of health interventions for people with intellectual disability through their changing health status. In 2013, the Ministry of Health published a literature review and case studies illustrating good practice examples for health care providers.¹⁹

There has been some ongoing work led by government as a result of the report's disturbing findings. 'The New Zealand Health Strategy: Future Direction'²⁰ includes an action proposing targeted investments for populations with high needs as one means to achieve its overall goal that "all New Zealanders live well, stay well, and get well."

The Ministry of Health launched its 'Achieving Equity in Health Outcomes' programme in 2018 in recognition that health inequities are "not only avoidable but unfair and unjust". The 2019 summary report on this programme primarily focusses on actions to improve health inequity for Māori and Pasifika in New Zealand.²¹ The programme is founded on the understanding that "equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes". Given this, it has significant potential value for New Zealanders with intellectual disability if its scope permits.

The Government's "Disability Action Plan (2019-2023)" states that improving health outcomes is a priority. In early 2015, the Ministry of Health established a reference group on 'Improving Health Outcomes of People with Learning Disabilities' to identify actions and interventions. It identified a number of strategic outcomes, actions and recommendations accordingly. The reference group was disbanded in 2018.

¹⁸ Based on data for a different period 2012-2014, cited in 'The contribution of avoidable mortality to the life expectancy gap in Māori and Pacific populations in New Zealand—a decomposition analysis' by Michael Walsh, Corina Grey. *New Zealand Medical Journal*. March 2019 Vol 132.

¹⁹ *Providing Health Services for People with Intellectual Disability: Literature review and case studies*. (2013) Wellington: Ministry of Health.

²⁰ *New Zealand Health Strategy: Future direction*. 2016. Wellington: Ministry of Health.

²¹ *Achieving Equity in Health Outcomes: Summary of a discovery process*. (2019) Wellington: Ministry of Health.

The 2019 work programme of the Ministry's Disability Directorate continues to specify some actions to improve access to health care for people with disability, and people with intellectual disability in particular.²² Currently a small team within Disability Directorate has resumed a work programme which includes options to improve the health outcomes of people with intellectual disabilities, particularly in relation to their lower life expectancy rates. There is growing recognition that efforts to this end will need to broaden scope beyond disability services alone. However, a clear systemic mechanism to manage the interfaces between health and disability sectors is not obvious to people outside the government and public sector, and frustration is high.

Premature Deaths

We know that people with intellectual disability die younger than average by some significant amount and from conditions that are not always the same as found in the wider population.²³ Such deaths are often described as premature.

The 'Confidential Inquiry into Premature Deaths of People with intellectual Disability' (CIPOLD) report²⁴ also analysed causes of death compared with a non-intellectually disabled comparator group. This makes it a powerful report, as it removes variables perceived to be specific to the individuals' impairments. In doing this, the CIPOLD team identified four sets of contributors more commonly observed in deaths of people with intellectual disabilities:

1. Individual – such as dependence on others for mobility, communication or feeding
2. Family and environmental – such as poverty, social exclusion, families not being consulted or listened to
3. Care provision – such as problems with planning care, sharing information, reasonable accommodations to needs
4. Service provision – such as legal authorisations (Do Not Resuscitate orders, end of life planning), timely diagnosis, and treatment.

Clinicians and mortality researchers also try to distinguish those deaths which may have been avoided given effective and timely health care. These are referred to as 'amenable deaths'.²⁵ So defined, they align with concerns expressed in disability mortality literature. One might also refer to avoidable deaths, such as accidents resulting from inattention or errors in caregiving. All contribute to death rates for a population often reliant on the vigilance of others to identify health or safety concerns, and support to access information, aids, and assessment for diagnosis and intervention.

Cases of premature and unexpected deaths of people living with family or in care continue to cause concern to affected families, and generate media attention internationally.²⁶ They highlight issues of

²² Ministry of Health Briefing paper to Health Ministers (7 August, 2019). Health Report: Disability Action Plan 2019-2023: draft work programmes for your approval. Provided under OIA request.

²³ Mortality in People with Intellectual Disabilities'. Heslop.P., Lauer. E., and Hoghton. M. Journal of Applied Research in Intellectual Disabilities 2015, 28, 367–372.

²⁴ www.bristol.ac.uk/cipold

²⁵ Defined as premature deaths occurring under 75 years that could potentially be avoided given effective and timely healthcare. From "Defining Amenable Mortality" Ministry of Health 2016

²⁶ Harrison Creevy (Australia). "Disabled teenager dies after flu complications, parent claim medical response inadequate", online media story ABC News 27/7/2019 accessed 22 February 2020.

<https://www.abc.net.au/news/2019-09-27/harrison-creevey/11551564?nw=0>

Nathan Brooker (New Zealand) drowned in bath while in respite care:

<https://www.rnz.co.nz/news/national/313692/teen-should-never-have-been-left-alone-in-bath-watchdog>

"Justice for Laughing Boy: Connor Sparrowhawk- a Death by Indifference", Sara Ryan (2018) Jessica Kingsley publishers. Connor Sparrowhawk (England) drowned in bath in an inpatient mental health unit.

access to quality and timely health care and to lapsed standards of disability support. They also provide insights into which deaths may have been avoidable, or amenable, such as the risks of drowning while in the bath, and risks associated with communication between families and health care providers. Significantly also, premature deaths leave families, friends and caregivers as well as health providers wondering, asking questions, and with unresolved grief.

New Zealand mortality research

The Ministry of Health’s Mortality Collection (MORT) provides generic population mortality data on causes of death for New Zealand’s vital statistics. Its database contains underlying cause of death data for all registered deaths and stillbirths in New Zealand.

Mortality data is used for public health research, policy formulation, monitoring the effectiveness of health programmes, and cancer survival studies. The government and its agencies have used mortality data to highlight patterns across age and gender and ethnicity, particularly so it can focus on parts of the population whose health status is of concern. Examples are mortality at childbirth and in infancy, and Māori mortality at various ages. Records of changing life expectancy across many years illustrate the sustained improvement in health of New Zealanders.

The Mortality Collection team produces annual reports. These comprise population level reports of mortality and demographics data (age, ethnicity, sex, geography, and cause of death). It also produces annual specific reports such as Fetal and Infant Deaths, or on Suicide Facts. The Mortality Collection team can also customise datasets or summary reports on request.

There is also New Zealand mortality research based on ‘amenable’ deaths. The concept of amenable deaths is interesting. Reports published using New Zealand data are based only on 35 agreed health conditions that determine amenable deaths. Current research on amenable deaths would not be able to identify those who live with intellectual disability, unless those individuals had a co-morbid health condition within the agreed terms.

The 2011 Health Indicators report provided some information on life expectancy and drew from MORT for that data. The table below uses data from the MORT collection and from the Health Indicators report findings to compare life expectancies for male and female Māori, and highlights the significant discrepancy for both disadvantaged groups compared with the general population, but for people with intellectual disability in particular.

New Zealand Life Expectancy at birth comparisons: Māori and people with intellectual disability

| | Life Expectancy - in years | Discrepancy against population as whole |
|---|-------------------------------|--|
| Non Māori male | 80.3 | - |
| Non Māori female | 83.9 | - |
| Māori male | 73.0 | 7.3 |
| Māori female | 77.1 | 6.8 |
| Intellectual disability male * | 59.7 | 18.0 |
| Intellectual disability female * | 59.5 | 23.0 |

Jack Sullivan (Australia) drowned in bath while in respite care.
<https://www.smh.com.au/politics/federal/searching-for-honest-answers-20120914-25xlf.html>

* based on 2009, where average life expectancy of all New Zealanders was 77.7 and 82.5 respectively. As reported in 2011 Health Indicators study.

Todd et al 2013²⁷ reported on what information a large New Zealand disability provider held about those had died within its services over a two-year period. It reported that 97 people with intellectual disability had died in that period, of whom 65 were adults in residential care settings (group homes). The report estimated the crude death rate to be 13.1 deaths per thousand compared with New Zealand's crude death rate of 6.82 per 1000 (in 2012).

4. TERMINOLOGY

The health and disability sectors, as well as the agencies involved with monitoring the wellbeing and mortality of people with intellectual disability operate under legislation and terminology specific to their respective purposes. I will therefore discuss terminology for its significant influence on the challenge facing any future work – how intellectual disability is defined and my recommendations for future work; and how care is defined and my suggestion on how to apply this term.

Defining intellectual disability

Disability serves as an umbrella term for impairments, activity limitations, or restriction in participation (International Classification of Functioning, Disability and Health, ICF, 2005).

This project is focussed only on those people whose disabilities relate to significant learning and cognitive impairments. Reaching common agreement on defining intellectual disability is difficult. It largely refers to the relationship between significant limitations in a person's general intelligence and resulting impairments in typical daily functioning. Living with an intellectual disability manifests in many different ways as a person engages in daily life, makes decisions, seeks and responds according to their needs and preferences.

When Stats New Zealand reported on the challenges it faced in measuring the prevalence of disability, and integrating information from multiple sources, it noted many instances of terminology that mixed names, definitions, and classifications.²⁸

For this project, I have adopted a definition of intellectual disability commonly applied in New Zealand disability sector and in international disability research.

Intellectual disability is a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18.²⁹

Terminology is also influenced by the perspective of people living with intellectual disability. People with intellectual disability are incredibly diverse in their wishes, world experience and aspirations. However they are often seen as a homogenous group, and their lives, health and wellbeing are interpreted solely through a disability lens. This adds to resistance about labels, especially medicalised

²⁷ Place of death of people with intellectual disabilities: An exploratory study of death and dying within community disability service settings (2019) Journal of Intellectual Disabilities. Stuart Todd, Sharon Brandford, Rhian Worth, Julia Shearn, Jane Bernal [DOI: 10.1177/1744629519886758](https://doi.org/10.1177/1744629519886758)

²⁸ Measuring disability in New Zealand: Current status and issues – a discussion document for the Working Group on Disability Data and Evidence (2015).

²⁹ American Association on Intellectual and Developmental Disability AAIDD. <https://www.aaid.org/intellectual-disability/definition>

ones typically focussing on deficits. Many people living with disability resist medicalised terminology with its connotation that disabled persons are broken or sick, in need of fixing.

Ngā Tangatā Tuatahi - People First New Zealand³⁰ has indicated a preference for the term learning disabled. While acknowledging this shift in preferred terminology, I have retained the term intellectual disability for this report. This is the term most used in the government and international research sources drawn on for the purposes of this scoping project.

There are a variety of causes³¹ and consequences of intellectual disability, some of which have found their way into words synonymous with intellectual disability, for example, Down Syndrome, Fragile X. Others terms reflect past ways of conceptualising disability (imbecile, backward, slow, mentally deficient, intellectually handicapped, or mentally retarded).³² Over time, many of these terms have changed to reflect better understanding and reduce stigma. Some outdated terms still remain in circulation despite this. This variable use becomes particularly challenging when trying to extract information that might shine a light on health and mortality.

Diagnostic and clinical terms also frequently mix classifications of severity of impact (profound, severe, moderate, or mild intellectual disability). Indeed, in one Coroner's report viewed, the person was described as having a "slight disability". Each classification of severity is troublesome because there is an incorrect assumption for example that a person is uniformly impaired across social, life skill, and daily functioning domains.

Definitions in New Zealand legislation³³ increasingly align with standardised definitions used by clinicians and researchers. These definitions largely come from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and International Statistical Classification of Diseases (ICD-10).³⁴ They include three criteria:

1. significant impairment in intellectual functioning; and
2. significant difficulty in adaptive functioning – engaging in typical activities of daily living, requiring varying supports; and
3. these features are present during childhood and developmental years.

These criteria are applied by the Ministry of Health when determining eligibility for disability support.

World Health Organisation classification of intellectual disability (using ICD-10)

It is worth expanding on the international coding convention developed by the World Health Organisation for reporting diseases, injury, and health conditions, called ICD-10. The approach used in ICD-10 is critical because its codes are used globally by health providers for health statistics, datasets

³⁰ Nga Tangata Tuatahi People First New Zealand: Nothing About Us, Without Us. A New Zealand disabled persons organisation, providing self-advocacy for and by people with intellectual disability

³¹ Etiology is attributed to many factors, largely genetic or environmental factors. Exposure to environmental factors can occur in utero (e.g maternal rubella) or after birth (lead poisoning, oxygen deprivation).

³² Another term familiar to many is Mental Retardation. More commonly used in North American research and government records, it can reasonably be treated as a synonym for intellectual disability.

³³ The Intellectual Disability Compulsory Care and Rehabilitation Act 2003 (IDCCR Act). I believe the only exception is the outmoded definition used in the Contraception Sterilisation and Abortion Act (1977). Section 2(4) describes a mentally subnormal woman "if she is suffering from subnormality of intelligence as a result of arrested or incomplete development of mind to the extent that she is incapable of living an independent life or of guarding herself against serious exploitation or common physical dangers or ...is incapable of understanding the effective use of contraceptives or the desirability or need for their use."

³⁴ International Statistical Classification of Diseases and Related Health problems – tenth revision – 2nd edition (2004) https://www.who.int/classifications/icd/ICD-10_2nd_ed_volume2.pdf?ua=1

(including mortality collections), health policy and research, and most notably in agreed conventions for recording causes of death.

ICD code sets are grouped by specific injury or disease processes. Intellectual disability is specified under a group of medical conditions called Mental and Behavioural Disorders (F 70-79 codes).³⁵ However, ICD-10 also includes other medical and health conditions, some of which may have intellectual disability as a feature.

Indeed, Glover & Ayub (2010)³⁶ identified 48 ICD-10 codes for medical conditions usually associated with intellectual disability and 76 ICD-10 codes for conditions sometimes associated with intellectual disability. There is great potential therefore for variable use of codes when they are used in health records or in certificates of death.

Defining 'In care'

As outlined in the introduction to this report, my focus is on people with intellectual disability who die while 'in care'. I favour a broad definition of 'in care', namely:

Death of individuals receiving government-funded disability supports, whether provided for short or extended periods, to meet their health or disability support needs. It can apply to children and to adults.

Individuals supported by family are excluded from this definition, as to include them would open up a range of complex issues that are far beyond the scope of this report to grapple with. Despite this exclusion, the definition of 'in care' I have chosen to use here is broader than the definitions used by official bodies in New Zealand. Arguably, if the criteria for defining 'care' are overly prescribed, a substantial number of deaths involving people with intellectual disability will continue to be outside any formal systems of investigation or review. In my view, this is likely to exacerbate the invisibility of deaths, and reduce further our opportunity to respond differently.

To develop this definition I drew, primarily, on overseas disability research and mortality reviews. These sources also largely focus on people in care, and use definitions derived from that country's legislation and each review's purpose.³⁷ The definitions used internationally are typically broader in scope than the examples from New Zealand's statutory agencies or commissions described below. As a result they review significantly larger target populations.

Mortality reviews from Australia (Queensland, Victoria and New South Wales), the United Kingdom, and United States of America do not tend to limit their focus to those in official custody or court-ordered care.³⁸ Some also include the deaths of some people with disability who received drop-in support from a disability service provider, subject to conditions. The role of the state as provider or funder does not appear to be so critical.

³⁵ <https://icd.who.int/browse10/2016/en#/F70-F79>

³⁶ Cited in 'Mortality in People with Intellectual Disabilities'. Heslop.P., Lauer. E., and Hoghton. M. *Journal of Applied Research in Intellectual Disabilities* 2015, 28, 367–372.

³⁷ The purpose of most overseas research is to reduce preventable deaths, and to capture lessons about health access and provision as well as disability support provision.

³⁸ NSW mortality reviews cover people in residential care. That includes group homes, residential centres (institutions), assisted boarding houses, and other accommodation for people with disability, such as centre-based respite.

Regardless of the funding mechanism or legal process that got them there, these international examples acknowledge that people in such care arrangements are reliant on support of others to live their life and participate in their community. They acknowledge that people other than family have some formal role broadly interpreted as monitoring wellbeing.

In New Zealand, definitions of the term 'in care' have been more narrowly defined. This is primarily because of the legal and statutory scope of the organisation applying the definition. This has influenced the jurisdiction and scope of the Office of the Chief Coroner, the Royal Commission into Abuse in Care³⁹, the investigation by the Chief Ombudsman, and by disability services funded by Ministry of Health Disability Directorate.

Definitions based on New Zealand's Coronial processes

New Zealand's Coroners Act 2006⁴⁰ states that any death 'in official custody or care' must be reported to the police, and requires Coroner Court involvement. Official custody or care includes people under the care of the state; in police custody or in prison; a child under the care and custody of Oranga Tamariki⁴¹; people subject to compulsory treatment for mental health, alcoholism or drug use; or disabled people in compulsory care or rehabilitation subject to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act).

This stipulation for mandatory inquiry emphasises the particular vulnerability of people in the care and custody of the state, and therefore the state's obligation to understand the circumstances of their death. People subject to the IDCCR Act consequent on alleged criminal offending meet this criterion.⁴² Of course, a person with intellectual disability who dies may become subject to coronial processes if other criteria set by the law apply; for example if their death is caused by a vehicle accident.

117 coroners' reports specific to people with intellectual disability informed this scoping project (This is described in more detail later in this report under Investigations by the Coroners Court). This sample indicated that only 3.4% met the Coroners Act criterion of being 'in official custody and care' for mandatory coronial enquiry. Significantly more reports (47%) applied to people living in community residential care. Notably, the reports used a range of terms to describe the living and care arrangements, such as community institutions, facilities, group homes, residential homes, supported residential living.⁴³ The mix of terminology made it difficult to form an accurate assessment of the care settings people were in when they died.

Definitions based on investigation by New Zealand's Chief Ombudsman

As outlined earlier in this report, the investigation by the Office of the Ombudsman focussed on deaths of those in receipt of full-time residential support. Residential support was in turn limited to those residing in District Health Board and non-government community facilities, namely:

- Community Residential Support Services (CRSS), including support in a home-like setting; people with intellectual disability aged under 65 years, living in aged care facilities; and 'out-of-family' residential support services for children and young persons with intellectual disability;

³⁹ The Royal Commission into Abuse in Care includes both residential and residential settings as 'state care'.

⁴⁰ Coroners Act 2006, section 9 <http://www.legislation.govt.nz/act/public/2006/0038/latest/whole.html>

⁴¹ Ministry for Children: a statutory government agency administered by Ministry of Social Development.

⁴² An experienced Medical Referee suggested that deaths of people subject to the IDCCR Act may be under-reported, observing that certifying practitioners can be unaware of the person's legal status because their placement under the Act was many years before the death, or are unaware of requirements to report them to the Coroner.

⁴³ I used my own judgement to assign various descriptions as community residential care.

- People with intellectual disability who received care under the High and Complex Framework, being Regional Intellectual Disability Supported Accommodation Services (RIDSAS); and Regional/National Intellectual Disability Secure Services (RIDDS/NIDDS).

In setting the scope of his report, the Chief Ombudsman indicated he was influenced by the extent to which people with intellectual disability in community residential care were dependent on the care setting, and whose impairments may limit their freedom and self-determination. As a result, the terms of reference for his investigation differed from other care definitions in several ways:

- It excluded deaths of people in respite care, despite several high profile deaths in such settings in New Zealand.⁴⁴
- It excluded deaths of people living in their own homes (such as in supported living) and receiving other types of disability support from the Ministry, despite reports of the particular risks related to poverty and isolation.
- It excluded people over 65, which is the upper age for accessing disability support.
- It excluded deaths of children in out-of-family care funded through other government agencies (such as ACC or Oranga Tamariki).⁴⁵

Conclusions on Care Definitions

By focussing only on those who die in some situations, there is a risk that other variables are not considered, even if they contribute to premature death, such as costs of health services, or transportation barriers. Another effect of only looking at residential support is that it concentrates attention on the providers of that support, and away from other contributing factors. This is especially pertinent as we move away from institutional and traditional group home settings. With our focus on reducing premature deaths wherever a person lives, our attention will turn not only to the quality of service provision, but also issues in the quality of health services, and the complex interactions between them.

In Appendix 2, four care settings (described in service specifications for disability support funded by the Ministry of Health) would be captured within this broader definition of being in care. These are community residential care, aged care facilities, respite care, and Regional Intellectual Disability Supported Accommodation and Secure Services (RIDSAS and RIDSS).

5. HEALTH AND MORTALITY DATA SOURCES

*Good quality comprehensive disability data ... is essential to measuring progress towards these targets and goals, and ultimately their success.*⁴⁶

If we are to better address preventable and premature deaths, we need a way to identify people from existing data sets. This scoping project looked at what present data sources might be helpful to illuminate the situation regarding premature deaths of people with intellectual disability.

⁴⁴ See Health and Disability Commissioner reports on its website 16HDC00085, 10HDC00356

⁴⁵ There are a number of government agencies involved in funding care in New Zealand, in addition to Ministry of Health's Disability Directorate. This includes ACC, MSD through Oranga Tamariki, and Education through some residential schools.

⁴⁶ Making Visible the Invisible: Why Disability-Disaggregated Data is Vital to "Leave No-One Behind" Ola Abualghaib, Nora Groce, Natalie Simeu, Mark T. Carew and Daniel Mont, in Sustainability 2019, 11, 3091; [doi:10.3390/su11113091](https://doi.org/10.3390/su11113091)

Three data sources have been most relevant to this project:

1. Survey data –New Zealand’s five yearly census and the disability survey, conducted in alternate census periods.
2. Administrative data – includes records accumulated for administrative purposes through District Health Boards, government department divisions, the Coroners Court, integrated data index, etc.
3. Research data – refers to information and analysis in peer-reviewed literature, largely overseas.

A Disability Data and Evidence Working Group (DDEWG) was established in 2015⁴⁷ in recognition that disability data in New Zealand was not meeting international obligations under the United Nations Convention on the Rights of Persons with Disabilities. The Working Group contributes to resolving ongoing challenges in getting strong evidence to government to inform sound policy and services to meet the needs of disabled people in New Zealand. The most recent publicly available information about its progress on the Office of Disability Issues website is from 2018.⁴⁸ I understand the Working Group is developing indicators for a disability outcomes framework, which may or may not include data sources such as New Zealand’s Mortality Collection.

In 2015, Stats NZ did a stock-take of government datasets related to disability and described this in some detail⁴⁹. In summary, information gathered from diverse sources such as surveys, administrative data sets, and census reports refer to disability in different ways. This hampers the ability to amalgamate information.

Survey data

New Zealand undertakes a census every 5 years. Since 1996, Stats NZ has also conducted a Disability Survey in the census year (drawing its sample from two census questions) to get important information particular to people with disability living in New Zealand.⁵⁰

The Disability Survey asks an internationally standardised set of questions⁵¹ whereby information is collected on a functional basis: asking about difficulty that individuals experience across the areas of vision, hearing, mobility, remembering, self-care, and communications.

Data from these surveys is not broken down by impairment types. While addressing a number of issues, such an approach doesn’t provide helpful information when trying to identify variations or inequities within impairment subpopulations.

⁴⁷ Under the joint management of Department of Statistics/Stats NZ and the Office for Disability Issues

⁴⁸ <https://www.odi.govt.nz/nz-disability-strategy/outcome-8-leadership/action-implement-disability-data-and-evidence-work-programme/>

⁴⁹ Measuring disability in New Zealand: Current status and issues. A discussion document for the Working Group on Disability Data and Evidence. Statistics New Zealand (2015)

⁵⁰ In the 2018 Census, the Disability Survey was not conducted; instead data on disability was extracted directly from the census. The Government intends to schedule a disability-specific survey after the 2023 population census and every 10 years thereafter.

⁵¹ Washington Set of Questions. Washington Group on Disability Statistics (2006)

Administrative data

As has already been discussed, mortality datasets are another source of data, reporting analyses of death causes for all deceased people in New Zealand according to internationally agreed categories based on the ICD 10 coding system.

New Zealand does not have an agreed mechanism for patient-level data to reliably identify if a person has an impairment leading to disability. The 2020 Review of New Zealand's Health and Disability system acknowledges this omission.⁵² It recommends New Zealand consider a 'disability flag' to improve data collection and sharing of disability data across the health and disability system and with other government agencies.

Within the Ministry of Health's Disability Directorate, disability service allocation does distinguish between different impairment types. In the main, this is not the case for primary health care and District Health Boards, which are important collectors of administrative data about the health status of individuals or groups within the population.

Government and non-government agencies also collect information and hold this in databases usually designed for their unique purposes. Not all use the same terminology or codes when it relates to people with intellectual disability and are more likely to use a mix of descriptors of functional impairments and diagnostic terms akin to health-related categories.

There are significant challenges when drawing from multiple administrative data collections.

Research data

Academic research often uses both survey and administrative data sources as well as data collection through interviews and observations to enrich our understanding. There have been some significant and large prevalence studies that have integrated different datasets to generate robust results.⁵³ An example is the dataset from the Australian Institute of Health and Welfare (AIHW). This is a statutory agency linking health and welfare data from a range of sources and topics. Its datasets have been used by Professor Julian Trollor and colleagues to report on causes of death.⁵⁴ Professor Trollor is an internationally regarded researcher holding the inaugural Chair of Intellectual Disability Mental Health at the University of New South Wales. A number of his publications are cited in this report.

The New Zealand Government has a similar cross-government mechanism called the Integrated Data Infrastructure (IDI) to enable high level extraction and analysis of data from multiple government sources. The IDI has the potential to be of great value in extracting accurately those deaths which

⁵² Health and Disability System Review. 2020 – Final Report – Pūrongo Whakamutunga. Wellington: HDSR. www.systemreview.health.govt.nz/final-report. p128

⁵³ '2014 Preliminary Mortality Report. Commonwealth of Massachusetts, Department of Developmental Services'. Emily Lauer, Centre for Developmental Disabilities Evaluation and Research (CDDER), University of Massachusetts Medical School

Mortality among a Cohort of Persons with an Intellectual Disability in New South Wales, Australia. Florio. T. and Trollor. J. *Journal of Applied Research in Intellectual Disabilities* 2015, 28, 383–393

⁵⁴ Trollor J, Srasuebkul P, Xu H and Howlett S (2017) Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data, *BMJ Open* 2017: 7 <https://bmjopen.bmj.com/content/7/2/e013489>.

Reppermund S, Srasuebkul P, Heintze T, Reeve R, Dean K, Emerson E, et al. (2017). Cohort profile: a data linkage cohort to examine health service profiles of people with intellectual disability in New South Wales, Australia. *BMJ Open*, 7, e015627. <https://doi.org/10.1136/bmjopen-2016-015627>, [10.1136/bmjopen-2016-015627](https://doi.org/10.1136/bmjopen-2016-015627)

relate to people with intellectual disability, along with social, economic and health factors related to each person. Its application specifically to health and mortality data sources is yet to be comprehensively explored to determine its value for the purposes discussed in this report.

Disaggregation or not?

Article 31(2) of United Nations Convention on the Rights of Persons with Disabilities calls on member states to ensure there is disaggregated data collection with regard to disability; to ensure that disability is visible in general data collections.

Within New Zealand and internationally, disaggregating health and mortality data is a necessary first step if we are to put a spotlight on a group of people who have consistently been shown to experience higher rates of exclusion, and poor health outcomes.⁵⁵

New Zealand's disability-related data is mainly aggregated, and people with disability are largely unidentifiable from within the population datasets such as the Census, and its associated surveys. This issue is acknowledged in New Zealand's Disability Action Plan (2019-2023), which includes a specific recommendation and work stream to ensure data is disaggregated by disability.⁵⁶ Later in 2020, the first product of that commitment will be evident with the publication of Health Survey about the health outcomes of disabled people vs non-disabled people. The methodology does not differentiate by types of impairment,⁵⁷ but is a positive start. It may offer greater visibility for District Health Boards about the diversity of their populations, and where they might make reasonable accommodations.

Not everyone would support the introduction of disability coding or identification into health and mortality data sets, as proposed by the Review of Health and Disability Services.⁵⁸ Some people living with disabilities argue that categorisation and labelling compounds stigma and negative perceptions, and therefore should be resisted. If it has a place in any records, some argue disability is more like a demographic characteristic (such as sex, or age or ethnicity). Others actively seek a mechanism where their disability is registered and recorded so they get the benefit of reasonable adjustments and access to appropriate supports.

There is also debate about differentiation within disability, based on types of impairment. This argument posits that the health support needs and issues of people will vary according to the type of impairment. These are matters of ongoing debate with strongly held positions on all sides.

I sought to know what level of detail specific to people with intellectual disabilities could be extracted from administrative datasets held by statutory agencies. My findings illustrated an international challenge of extracting death-related information specific to people with intellectual disability from most current surveys and administrative data sets.

⁵⁵ The International Disability Alliance a worldwide alliance of more than 15 member organisations who affirmed their commitment to data disaggregation in a Joint Statement in 2017.

<http://www.internationaldisabilityalliance.org/data-joint-statement-march2017>.

⁵⁶ Stats NZ and the Office for Disability Issues co-lead a work programme through the Disability Data and Evidence Working Group.

⁵⁷ It uses the Washington set of 6 questions, which elicit information on the functional effects of impairments. The Washington Set are not used for children and are known to poorly reflect the issues for people with cognitive impairments such as intellectual disability.

⁵⁸ See footnote 52

The Disability Directorate was the only statutory body which applied data descriptors or codes specific to intellectual disability. It did this when reporting on the allocation of disability service types for specific parts of the disability population (such as people with physical or intellectual disability).

Other agencies' databases were designed to meet their primary work needs, but several had word-searching capacity to extract intellectual disability-specific information from text. But as has already been demonstrated, a diverse range of terms are used to apply to people with intellectual disability and their care arrangements. The Mortality Collection draws from Medical Certificates of Cause of Death and uses international coding conventions that bring both powerful strengths, but also some limitations particular to coding of intellectual disability. This is described in more detail later in this report under Death Certification.

6. ESTIMATING THE SIZE OF THE POPULATION IN SCOPE

It appeared reasonable to estimate how many New Zealanders with intellectual disability might die annually, since we have this information for some sections of our population already. Knowing the size of the population of concern, we could compare death rates across age groups and with the wider general population. Therefore, I used publicly available data to estimate the number of people within the scope of this report. I recognise that there will be other approaches, and encourage further dialogue about this.

How many people with intellectual disability are there in New Zealand?

Simply stated, we don't know for sure. We don't count them.

The Ministry of Health's report 'Health Indicators for New Zealanders with Intellectual Disability' 2011⁵⁹ referred to the lack of up-to-date data as a key factor complicating their work. Ten years on, this concern still applies. The following estimates draw from different time periods, and assume only minor variations in numbers and trends across the year periods pertinent to each data set used.

Internationally, the reported prevalence of intellectual disability varies between 1% and 3%. New Zealand's Health Indicators report (based on data from 2007/2008 population samples) estimated the prevalence of intellectual disability in New Zealand's population to be 0.7%. Estimates from the 2006 Disability Survey reported a 1.3% prevalence rate. This increased to 2% in the 2013 Disability Survey, but may have been elevated by people with neurological impairments. I have applied a middle figure of 1.3%, and used official records that indicate the estimated population of New Zealand in 2016 was 4.69 million.⁶⁰

Using these parameters, there would have been an estimated 60,970 people with intellectual disability in New Zealand in 2016.

⁵⁹ Ministry of Health. 2011. Health Indicators for New Zealanders with Intellectual Disability. Wellington: Ministry of Health. <https://thehub.swa.govt.nz/resources/health-indicators-for-new-zealanders-with-intellectual-disability/>

⁶⁰http://archive.stats.govt.nz/browse_for_stats/population/estimates_and_projections/NationalPopulationEstimates_HOTPA30Jun16.aspx#gsc.tab=0

How many people with intellectual disability are in care?

The following section describes what numbers can be extracted from different care arrangements. It highlights that people with disability live in a vast array of formal and informal care arrangements, varying in the degree to which ancillary funded supports are provided by others.

The data from the Ministry of Health's annual demographic report 2017⁶¹ is perhaps helpful as it breaks down the disability support allocation by disability type. That report indicated that in 2016, the Ministry of Health allocated disability supports to 7,246 people with intellectual disability who fitted my broader definition of being in care. They are listed below.

'In care' Disability Service Descriptions (using Service Specification titles)

| | |
|--|--------------|
| Community residential care | 5,416 |
| Choices in Community Living (residential care with greater choice and control) | 115 |
| Aged care | 21 |
| Short term respite services | 1,452 |
| High and Complex framework (including RIDSAS and RIDSS) | 244 |
| Total | 7,246 |

Additional to the 7,246 above, an unknown number of people with intellectual disability would have been in mental health inpatient services (funded by District Health Boards [DHBs])⁶², in prison (funded by the Department of Corrections), in youth facilities or foster care (funded by the Ministry of Social Development), or in support arrangements funded through the Accident Compensation Corporation. It is likely these numbers are small, but I mention them because such placements fall within the Coroners Act definition of official care or custody, and any such deaths would require Coronal scrutiny.

Far larger numbers of children and adults with intellectual disability were allocated and used disability supports in their own home or in a family's home. I deemed such support to be outside my definition of being in care, and excluded them from my calculations. The Ministry of Health service specifications refer to these as Supported Living, Carer Support, and Home and Community Support. The table below illustrates the scale of disability support allocation for these supports compared with those meeting my definition of 'in care'.

'Not in care' Disability Service Descriptions (using Service Specification titles)

| | People with intellectual disability |
|---|--|
| Supported Living | 2,321 |
| Home and community support | 4,183 |
| Carer Support (primarily used by families for children) | 8,452 |
| Enabling Good Lives (EGL) | 98 |
| Individualised Funding (IF) | 1,307 |
| Enhanced Individualised Funding (EIF) | 185 |
| Total | 16,546 |

⁶¹ Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services as at September 2016. Ministry of Health (2017).

⁶² There are people with intellectual disability subject to MH(CAT) Act, who are in official custody or care as per Coroners Act criteria. People in inpatient care are recorded in DHB mental health database (PRIMHD), but this does not record disability.

Also excluded are people whose support is funded via three funding mechanisms – Enabling Good Lives, Individualised Funding, Enhanced Individualised Funding – introduced by government to maximise self-determination, control and choice about what services to use their funding allocation on. The data does not indicate whether the supports purchased through these funding models would fit any definitions of ‘care’.

How many people with intellectual disability die each year?

Simply stated, we don’t know. Their deaths are lost inside a range of data collections. New Zealand’s mortality collection enables us to know how many people with shared demographic features die (age, gender, and ethnicity) and how many die from specified causes. Extraction of detail about people with intellectual disability and their deaths appears to be much more difficult. As a result we cannot say in New Zealand whether any of these people’s deaths were avoidable, preventable or premature, as is suggested by overseas research.

I generated crude estimates in three ways using existing data collections:

- Path 1. By looking at disability-specific data sources (Ministry of Health Demographics reports)
- Path 2. By looking at population crude death rates and intellectual disability prevalence data; and
- Path 3. By looking at deaths reported to the Disability Directorate from contracted residential providers.

Appendix 2 describes in detail the calculation methods using these three different paths to estimate how many people with intellectual disability die annually, as well as cautions applicable to each data source.

From the variable data available between 2013 and 2016, I found the following:

- Past Ministry of Health Demographics reports about disability, in which death numbers were reported (though not in 2016), estimated 201 people with intellectual disability may have died in 2016.
- By extrapolating from disability prevalence data to the crude death rates for the general population provided by the Mortality Collection, an estimated 217 people with intellectual disability may have died in 2016.⁶³
- By extrapolating from the Chief Ombudsman’s investigation of deaths reported to the Ministry of Health’s Disability Directorate, we would expect an estimated 119 deaths annually just among those in residential care for their inquiry period (2016-2018).

A conservative estimate is that there are at least 200 deaths per year using data from the 2013 to 2016 period. This is likely to be a low estimate because the death rates for people with intellectual disability are reported to be higher than those in the general population.

⁶³ Researchers of disability mortality recommend using another measure, Standardised mortality rate (SMR) rather than crude death rates as it provides a better measure of excess deaths in people with intellectual disability. (Heslop, Lauer and Hoghton 2015, see footnote 24).

Summary of estimating the size of the population in scope – based on 2016 figures



As far back as 2008, a UK government report articulated clearly this invisibility within datasets.

“People with learning disabilities are not visible or identifiable to health services, and hence the quality of their care is impossible to assess. Data and information on this sub-set of the population and their journeys through the general healthcare system is largely lacking and what exists is inadequately co-ordinated or understood.”⁶⁴

Sadly, the key finding from that report describes the current capability of New Zealand data collections to estimate the size of the population of central concern here.

7. REPORTING DEATHS

Health sector reporting of deaths

Health service providers – primary health, District Health Board, community health, and others – are required to report adverse events to the Health Quality & Safety Commission (HQSC). The Commission runs an Adverse Events Learning Programme (AELP) that aims to improve patient safety by supporting organisations to identify, report, review, and learn from adverse events.⁶⁵

A death might be an adverse event if there is no connection with the natural course of an illness or different from the outcome you would expect from its usual management.

Disability sector reporting of deaths

The HQSC also encourages providers of disability support to report adverse events, although such reporting is not mandatory for them. HQSC’s annual reports confirm that few use this mechanism.

The Adverse Events Learning Programme (AELP) uses terminology and processes from the health sector. It is beyond the scope of this project to comment whether this process is ‘fit for purpose’ when applied to disability support provision and people who may well not be patients within a health setting. The NZ Disability Support Network indicated there was currently no work programme

⁶⁴Michael J, Richardson A. Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Vol. 13, Tizard Learning Disability Review. 2008. p. 28–34.

⁶⁵ National Adverse Events Reporting policy 2017. <https://www.hqsc.govt.nz/our-programmes/adverse-events/publications-and-resources/publication/2933/>

between HQSC and disability providers for the oversight of critical incidents.⁶⁶ The Chief Ombudsman has recently recommended this begins.

Instead, disability providers contracted to the Ministry of Health are required to report deaths of people in residential care to the Ministry. This occurs through a Death Notification Form, designed to record minimum demographic and administrative information. The Chief Ombudsman's 2020 investigation indicated serious shortcomings in the Ministry's scrutiny and utilisation of information in reporting records from providers.

It appears there is also significant variation in the detail received from providers. In the past this variation may have been tolerated because the Ministry of Health didn't systematically use information on Death Notification forms for any consistent purpose. In 2019, the Ministry introduced new internal procedural requirements once providers report a death. It is too early to see if these operational changes and other actions arising from the Ombudsman's report are effective in focussing attention on equitable access to health and disability supports.

Could other agencies report on deaths of people with intellectual disability?

At least three agencies appear to have authority set in their legislation to undertake special reports. These are the Child and Youth Mortality Review Committee (CYMRC), the Coroners Court, and the Health and Disability Commissioner (HDC). This is encouraging. Those interviewed for this project universally expressed positive interest in this project and its target focus.

The primary purpose of their special reporting capacity is to extract and share lessons. This is also encouraging. None of the agencies consulted had yet undertaken special topic reports on people with intellectual disability, but several specifically indicated that people with intellectual disability could potentially be the focus for future special reports.

What triggers Special Reporting?

Mortality reporting about specific populations appears to occur as a result of political and evidence-based indications of the need. Some population groups are the subject of annual reports by virtue of demographic factors, such as maternal mortality, fetal and infant mortality. Others are reported annually by the Mortality Collection based on cause of death, such as cancer, and youth suicide.⁶⁷

It does not appear to be just numbers that trigger special reports. In 2016, for example, the Mortality Collection reported on 210 infant deaths, and the Chief Coroner published a special report on 10 deaths related to recreational hiking in its quarterly Recommendation Recap summary.

There are procedural challenges in generating a special report for a population group with no easily identifiable demographic features, and no single cause of death. I believe there is great potential for this special reporting capacity to be applied to the subjects of this report.

⁶⁶ Personal communication, Dr Garth Bennie, CEO NZDSN 28 June 2019

⁶⁷ 9,517 people died from cancer-related deaths; 553 people died from suicide, (Mortality Collection 2016)

8. DEATH CERTIFICATION

The government has begun the process of reforming our system of death certification as part of a wider review of the Burial and Cremation Act 1964.⁶⁸ The Law Commission's report supporting the review recommends a number of changes to the complex system. Current roles and processes regarding certification most relevant to this report are briefly summarised below.

Medical Certificate of Cause of Death

New Zealand has a comprehensive system for recording deaths. Our government and the health sector in particular uses these records (death certificates) to set and monitor policies, and to allocate large volumes of health resources. There are a large number of administrative forms prescribed for use at different stages of the notification and reporting of deaths. Some of these have been identified for amendment under the review of the Burial and Cremations Act.⁶⁹

Of chief interest to this project is the Medical Certificate of Cause of Death (MCCD), often referred to as the 'doctor's certificate'. I will refer to it as the MCCD. This record is used in all deaths except those of babies dying within 28 days of birth. To add to confusing terminology, the MCCD is not the 'death certificate', though easily confused with it.⁷⁰

The MCCD primarily exists to do as its title suggests; record the cause of death. It has two parts:

Part 1

- a) the disease or condition directly leading to death;
- b) any antecedent causes of death;
- c) any underlying cause of death.

Part 2

- a) any other significant conditions contributing to the death but not related to the disease or condition causing death.

The Law Commission's review of the current Act reports errors in miscoding and inconsistency in coding practices when completing these parts of the MCCD, particularly where a deceased person had chronic conditions and co-morbidities. Coding errors are also reported overseas. According to the Law Commission's review, certifying health professionals in New Zealand receive inadequate training on how to complete these critical records, and are under considerable time and resource constraints to do so.

For this project then, there was value in learning about the safeguards in place to minimise errors and maximise accuracy of the resulting datasets, particularly in relation to people with intellectual disability.

Mortality Collection (Ministry of Health)

Chief among the safeguards for accurate recording of causes of death is the team within the Ministry of Health responsible for the Mortality Collection (MORT).

⁶⁸ Law Commission. Final Words: Death and Cremation Certification in New Zealand (NZLC IP23, 2011) Death, Funerals, Burial and Cremation: a Review of the Burial and Cremation Act 1964 and Related Legislation (2019) Ministry of Health.

⁶⁹ Ministry of Health. 2019. 'Death, Funerals, Burial and Cremation: a Review of the Burial and Cremation Act 1964 and Related Legislation'. Wellington: Ministry of Health. Reported as 70% on p99

⁷⁰ The death certificate is issued by the Registrar-General of Births, Deaths and Marriages after a death has been registered.

Skilled coders in the team clean the information they receive and rigorously assign codes to the death based on information from the Medical Certificate of Cause of Death (MCCDs) and other sources (such as a Coroner's findings)⁷¹. Once cleaned and collated, the resulting annual datasets are linked through to the World Health Organisation for international comparison of mortality statistics.

Critically for this project's purpose, the international coding convention used by the MORT coders is based on ICD-10, identified earlier in this report as having a strong medical basis, and where intellectual disabilities might be variously coded.

It was beyond the scope of this project to meet the coders in the Mortality Collection Team and discuss issues relating to coding deaths for people with intellectual disability, but it is generally understood that the team uses internal monitoring processes to enhance consistency of their coding decisions.

The MORT team has been improving the guidance it frequently gives certifying doctors to ease the administrative processes.

Medical referees (cremation)

The role of Medical Referee is another safeguard and monitor of the quality of an MCCD. The Medical Referee system is prescribed in legislation. It is used only for cremations, which are the most common form of disposal of the dead in New Zealand. No body may be cremated without a Medical Referee.

A Medical Referee is an experienced medical professional contracted by crematorium operators to vouch that the cause of death recorded on a MCCD has definitely been ascertained, or the death has been referred to the coroner, and that there is no reason for further examination or enquiry. This is an important safeguard should questions of cause of death arise later, as cremation makes subsequent examination or autopsy impossible.

An experienced Medical Referee contacted for this report confirmed that many certifying practitioners are unaware of the guidelines on how to complete a form provided by the Ministry of Health⁷² or do not follow them. It was beyond the scope of this project to ascertain whether this understanding was shared by other Medical Referees.

Police and Coroners Court

Police can become involved when a death is unexpected. This usually occurs for deaths that are clearly not the result of a known illness, such as sudden deaths from a vehicle, workplace accident, or criminal harm. If Police attend a death, they will refer to a doctor or paramedic to confirm the fact of death and engage with other parties, such as a coroner, if cause of death is uncertain.

The Coroners Court is engaged when a death is of unknown causes – not related to a known illness. Coroners provide assistance to health professionals completing a MCCD who may be uncertain about whether to refer to the Coroners Court, which would then determine the cause of death through its own inquiry processes. From their inquiries, the content of the death certificate can be confirmed or amended.

⁷¹ In accordance with the World Health Organisation Rules and Guidelines for Mortality Coding. Pp31-98 in https://www.who.int/classifications/icd/ICD-10_2nd_ed_volume2.pdf?ua=1

⁷² <https://www.health.govt.nz/our-work/regulation-health-and-disability-system/burial-and-cremation-act-1964/completing-death-documents/medical-certificate-cause-death/completing-medical-certificate-cause-death-form>

Certification of deaths of people with intellectual disability

The recording of deaths on a Medical Certificate of Cause of Death becomes critically important if we are to identify and understand more about the deaths of people with intellectual disability. There has been significant research about the incorrect coding seen across many countries for many years. International research points to inaccuracies in the weight given to the person's intellectual disability on certificates.⁷³

There is no single ICD code for intellectual disability. The ICD system classifies the range of intellectual disabilities variably as a mental and behavioural disorder, or as chromosomal or congenital abnormalities in the cases of Down syndrome and spina bifida. The codes used depend on the knowledge of the certifying health professional, the coder, or the Coroner. Any of these codes could be ascribed as a direct cause, antecedent, or underlying cause contributing to cause of death.

As a result, it is quite possible to hear erroneous reports that a person "died from Down Syndrome". Manifestly, living with Down Syndrome does not cause one's death. Indeed, the Chief Ombudsman's 2020 report, 'Off the Record', found that 19% of its sample of reported deaths identified intellectual disability or a related specific condition such as Down Syndrome as the antecedent or underlying cause of death (part 1).

Most datasets and research on mortality extract information from the Part 1 sections of the MCCD, and this is important. Part 1 codes on a MCCD deal with the direct and immediately antecedent conditions that cause the death. If disability-related codes have any role in descriptions of cause of death, there is increasing consensus that they are best applied in Part 2 of a MCCD as an underlying condition contributing to death (but only if it actually contributed to that death).⁷⁴ According to the Medical referee who provided comment on their experience, certifying practitioners commonly omit underlying conditions such as intellectual disability or dementia.

These variations reflect the challenge of using a medical diagnostic system to identify a diverse subset of our population with significant limitations in general intelligence and their resulting impairments in typical daily functioning. It is important therefore that erroneous references to intellectual disability in Part 1 sections of an MCCD are minimised, and that underlying conditions such as intellectual disability are acknowledged in Part 2 where relevant. Some clearer guidance to certifying practitioners may enhance the usefulness of data resulting from future death certificates.

What makes a death unexpected or premature?

Making the determination about whether or not a death is unexpected is important because it is a trigger for closer scrutiny of an MCCD and possibly initiating investigative mechanisms. The quality assurance mechanisms provided by the Mortality Collection, Medical Referees, the Police, and Coroners become weaker if incorrect determinations are made about whether a death was unexpected. Believing a death was unexpected triggers scrutiny by others.

Clearly, determining that a death was unexpected requires not only a knowledge of the person's health status, age and the circumstances of the person's death and life. It is not reasonable to assume

⁷³ Landes SD, & Peek CW. (2013) Death by mental retardation? The influence of ambiguity on death certificate coding error for adults with intellectual disability. *Journal of Intellectual Disability Research* 57, 12, 1183-1190.

Landes SD, Stevens JD, Turk MA. (2019) Obscuring effect of coding developmental disability as the underlying cause of death on mortality trends for adults with developmental disability: a cross-sectional study using US Mortality Data from 2012 to 2016. *BMJ Open* 2019;9:e026614. [doi:10.1136/bmjopen-2018-026614](https://doi.org/10.1136/bmjopen-2018-026614)

⁷⁴Professor Nick Lennox, verbal communication 2019.

that certifying medical practitioners, police officers, coders, pathologists, and coroners have such knowledge about a person with intellectual disability, even though they will likely hold their own preconceptions about their life expectancy.⁷⁵

There is complexity about identifying what is an unexpected or premature death. It seems reasonable to suggest that whether or not a death is premature, within this population there is cause to consider circumstances, including whether the death was unexpected. It is only through looking at circumstance that you can make this assessment.

Many people with multiple disabilities live with chronic and complex health conditions, and sometimes these contribute to their death. In this context, a death might be deemed by others to be expected, indeed inevitable. Many families and people with complex disabilities recount experiences where the value of treatment is questioned by the treating physicians and health professionals.

*“They don’t really care because they think disabled person’s life is going to be short, they view disabled people as a burden”.*⁷⁶

This suggests the influence of others’ perceptions on determinations about whether a death was expected, and whether the certified cause of death needs to be verified or investigated further.

9. INVESTIGATIONS

Investigations into individual deaths occur in New Zealand in several ways, and there is overlap between the paths followed. Broadly, investigations can be ‘internal’ – generated by the provider of health and/or disability care for the person who died, or ‘external’ – carried out by an external agency. The nature of the investigation depends on the circumstances of the death, and the source of concern that triggers an investigation. Both have strengths as well as limitations.

Internal investigations

- Investigations can be conducted by the provider of disability care or a health providers, such as a District Health Board, general practice, or disability service provider.

External Investigations

- *Coroners Court*: where there is uncertainty about the cause of death, or where the deceased person was in the custody of the state.
- *Police*: There is liaison between Police and other statutory agencies when a death appears to be the result of a criminal offence, vehicle, or workplace accident. Police lead investigations according to different criminal-legislated authority.
- *Health and Disability Commissioner (HDC)*: HDC is an independent watchdog. It provides health and disability services consumers with a voice, resolving complaints, and holding providers to account for improving their practices at an individual and system-wide level. HDC does not investigate deaths of people in receipt of health or disability services per se – their trigger is a complaint about breaches to the Code of Health and Disability Rights.

⁷⁵ Example: it used to be relatively common for children with Down Syndrome to die in childhood or early adulthood due to heart conditions. Surgical advances have significantly enhanced life expectancy.

⁷⁶ Australian family member, cited in p36, “Walking backwards into the future: involving families in investigating the deaths of learning disabled”. Dr George Julian (2020) [George%20julian%20report%20WCMT.pdf](#)

- *Ministry of Health (Disability Directorate)*: requires contracted disability services to report deaths to the Directorate, such that the Disability Directorate might request an investigation, or monitor quality issues particular to the provider, or identify systemic issues regarding interface with health services.

Internal Investigations

Sometimes disability providers have internal policies and procedures for internal investigations when a person in their care dies. There does not appear to be a standard approach but it appears common that providers vary the depth of investigation depending on concerns.

However, all providers are required to investigate complaints. This is a contractual requirement and a core quality assurance measure embedded in health and disability standards. A provider will therefore undertake an investigation subsequent to a death of a service user if triggered by a complaint. Most complaints come from individuals or family members, but can also come from staff or allied agencies.

Providers have differing skill levels within their workforce, and will use clinical staff if they have them to assist investigations, or may commission this from elsewhere. Lessons from such investigations only tend to be shared internally. Anecdotal reports suggest providers do not believe they are required to provide internal investigation reports to the Ministry of Health, although they do provide them to statutory agencies such as HDC or the Coroners Court if requested.

The Chief Ombudsman's 2020 report found fewer than half the deaths of people in the care of such providers (reported to the Ministry of Health), had been investigated by the provider of the care. In a climate of increased accountability about safety, the low rate of internal investigation is a little surprising. There may be a number of contributing factors, such as:

- uncertainty about roles, or a deference to others (for example, the Coroner, Police), as expressed by officials within the Disability Directorate to the Chief Ombudsman;
- a lack of skilled personnel and resources to scrutinise health matters;
- attitudes about death that avoid 'looking death in the eye';
- attitudes and perceptions about death of people with intellectual disability;
- whether the death was expected and from natural causes;
- reluctance to open the service to blame.

Disability providers were not surveyed for this project, though received comments suggest value in further exploring barriers to internal investigations. For families seeking understanding about deaths of concern, resolution at this first stage through an open and honest process would be helpful. It would also be helpful if the roles and triggers for engaging external investigative bodies were better understood so that no worrying/concerning/unexplained death went unnoticed, and grieving families did not have to become complainants to ensure that a worrying death is investigated.

Internal provider investigations can also occur in conjunction with other investigations, for example an investigation into the responsiveness of ambulance services, or a Worksafe New Zealand investigation. The Office of the Health and Disability Commissioner can become involved whether or not a provider conducts its own internal investigation. Families may value the greater independence of such an independent agency's scrutiny.

Investigations by the Coroners Court

The Coroners Act 2006 sets the work of the Coroners Court. It stipulates situations where a coroner is legally obliged to look into a death, as well as situations where it might look into a death.

The Coroners Court must look into a death (either by an enquiry or inquest)⁷⁷ if a death:

- was unexpected
- was violent
- had no obvious cause
- was suicide
- happened while someone was being looked after by the State (in police custody, in prison, in an Oranga Tamariki home, in foster care or if they were a ward of state, under a mental health compulsory treatment order, being kept in an institute for alcoholism or drug use, being disabled and in compulsory care or rehabilitation)
- happened because of a medical operation.

Notably, these provisions do not apply to people supported by non-government disability providers, such as people living in a staffed group home. However, it does apply to a person with intellectual disability who died while subject to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (ICCR) or under compulsory mental health treatment.

The Coroners Court does not conduct inquiries to determine civil, criminal, or disciplinary liability. It has three prescribed purposes.

1. To establish, so far as is possible that a person has died; the person's identity; when and where the person died; and the causes of and circumstances of the death.
2. To make specified recommendations or comments that, in the coroner's opinion, may, if drawn to public attention, reduce the chances of the occurrence of other deaths in circumstances similar to those in which the death occurred.
3. To determine whether the public interest would be served by the death being investigated by other investigating authorities in the performance or exercise of their functions, powers, or duties, and to refer the death to them if satisfied that the public interest would be served by their investigating it in the performance or exercise of their functions, powers, or duties.

Not all deaths are subjected to coronial processes. In New Zealand about 3,600 deaths a year go through the process.⁷⁸ The Coroners Court faces significant workload pressure to meet its statutory obligations.

Apart from the specific obligations stated in the Coroners Act 2006 that inquiries must occur for people in the custody of the state, most other deaths of people with intellectual disability would only come under the investigative purview of the Coroners Court if someone – families or other concerned parties – requested an inquest due to uncertainties as to the cause of death.

For the purposes of this scoping project, I considered what public interest might trigger the Court's involvement. For example, Coroner W Bain (2011) canvassed the role of the Coroner Court in drawing public attention to matters related to recidivist drunk drivers. The coronial processes can enable deaths to be more widely discussed for policy and law change.

⁷⁷ An Enquiry is a hearing conducted on papers. An Inquest is a face to face process with calling of witnesses and evidence to assist the Court fulfil its obligations, and is called at the discretion of the Coroner.

⁷⁸<https://coronialservices.justice.govt.nz/assets/Documents/Publications/Chief-Coroners-Annual-Report-2018-2019.pdf>

Triggers applicable to this project's focus are:

- to highlight circumstances which might lead to other deaths, if not remedied, such as the risks of babies sleeping with parents
- to advance medical knowledge
- to allay rumours or suspicions for people who are worried about a death
- to preserve the legal interests of a deceased person's family, heirs, or other interested parties.

Coroners are provided with practice notes specific to issues of greater interest to the Coroners Court⁷⁹ usually on matters where there is mandatory death reporting. There are no current practice notes specific to people with intellectual disability in compulsory care, or on matters known to increase their risks for preventable deaths such as choking or aspiration, or challenges in communication and coordination across health and disability systems.

Some Coroners' reports are posted publicly on the Coronial Services (part of the Ministry of Justice) website⁸⁰, and this enabled me to get a first glance at some reports pertaining to people with intellectual disability. I was interested to learn how effective disability-specific inquiries might be to extract material from the substantial collection of coronial reports. The Office of the Chief Coroner provides a helpful coronial information service. On its advice, I submitted a request for a basic word search⁸¹ pertaining to reports for a five -year period (1 July 2011 to 30 June 2016).

This request generated the following information.

- A total of 117 reports were identified as having some reference to intellectual disability, ranging from 14 to 23 per year.
- Of the 117 extracted, intellectual disability could be verified within the report's content in 90 (77% of the total pool).
- Within the pool of 117, the average age at death was 49.
- Fewer than half were people who had been living in community residential settings (46.1%).⁸² Four were in court-mandated inpatient services.
- The majority of reports (73.5%) were treated as an Inquiry (a hearing done on papers). 23.1% had a full Inquest.
- 25% of the reports recorded intellectual disability on the Cause of Death details. Of these, 25% either stated it was the direct or antecedent cause of death (part 1 of Medical Certificate of Cause of Death (MCCD). The majority (over 75%) noted the presence of intellectual disability as a contributing factor (part 2 of MCCD).

This demonstrates that the Coronial Service database and report collection has some capacity to extract subgroups from a generic data collection of Coroners' reports. Particular to people with intellectual disability, there was information about their living arrangement that verifies the coronial process extends beyond placements "under the custody and care of the state" and into the array of disability and care services across New Zealand. It also confirms that 25% of the Medical Certificates of Cause of Death refer to intellectual disability, and only a few of these record it as the direct or indirect cause of death.

⁷⁹ s.132 Coroners Court Act

⁸⁰ <https://coronialservices.justice.govt.nz/findings-and-recommendations/findings-of-public-interest/>

⁸¹ disability, intellectual disability, developmental delay, Down Syndrome

⁸² NZ Coronial Information Services (20 June 2019). Reports used various descriptors of service types. 'Community residential' was applied when the report included references to being in a facility, having paid caregivers, living with others with disability, or under the care of an organisation.

Investigations by Health and Disability Commissioner

The Health and Disability Commissioner (HDC) has statutory functions arising from the Health and Disability Commissioner Act 1994. This legislation authorises the Commissioner to investigate complaints in relation to the Code of Health and Disability Rights.

It is important to note the HDC does not investigate deaths of people in receipt of health or disability services per se – their trigger is a complaint about breaches to the Code of Health and Disability Rights (the Code), and this is the focus of any inquiry by HDC, not a death. The Commissioner is unlikely to become involved where a death occurs to be the sole vehicle for investigation. I have included the HDC in scoping of investigation pathways because rights breaches have resulted in deaths. Families may use the complaint investigation processes of the HDC to find meaning from the death of their loved one.

The HDC undertakes a preliminary assessment of the care provided and decides on the appropriate process for resolving the complaint under s.33 of that Act. In some situations, the HDC sometimes conducts the first investigation if the key concerns relate to the quality of the health or disability service provided as this is its primary function.

The Commissioner has a role in educating the sector about health and disability rights and the Code. Publication is a key mechanism for sharing HDC's findings, although only those complaints where a breach of the code is found are published. A complaint involving a death may not be investigated formally if there is no evidence of a code breach, and therefore no publication of the Commissioner's finding published.

It would be a complex task to extract death-related events particular to people with intellectual disability from the Commissioner's database of investigations. The database is constructed around the subject of a complaint (that is, the type of health or disability service), rather than the individual whose rights have been allegedly breached.

Future work to collate lessons from reports where the HDC has found code breaches would require considerable effort and manual handling of its investigation findings.

Interagency liaison regarding investigations

It is clear that there are situations when multiple investigative paths are activated. This was evident in reading reports by statutory agencies such as the Coroners Court occasionally referring to internal providers' reports when these were available. Similarly the likelihood of this overlap is recognised through Memoranda of Understanding between the HDC and Coroners Court.

A Memorandum of Understanding is an appropriate mechanism to guide who gets involved and when. When matters are raised with the HDC where the cause and circumstances surrounding a fatality are key issues, the HDC steps aside for the Coronial inquiry process. Additionally, the HDC liaises with agencies such as the Ministry of Health to address broad issues related to care. The HDC views the capacity and capability of providers to meet the on-going demands of intellectually disabled consumers as an important area which warrants careful monitoring.

Concluding the work of a coronial process often requires significant liaison between the Coroners Court and other agencies and people contributing to its determination of cause of death. The extensive liaison required ensures quality information so that each agency can conduct its own work well, but effectively share the information. This can create a complex web, however, for bereaved

families and for providers who report both duplications in their work to support investigations and uncertainty about how they are to learn from their own or others' experiences.

10. DEATH REVIEWS

Reviews are not the same as investigations. Reviews look at a cohort of deaths and identify common issues that might indicate changes that would prevent further deaths for that specific group. They are generally regarded as a powerful vehicle for disseminating lessons to a wider audience.

Few reviews have been done in New Zealand. Those most relevant to this report are described below.

[The Health Quality & Safety Commission and Child and Youth Mortality Review Committee](#)

In New Zealand, five statutory committees report annually to the Health Quality and Safety Commission (HQSC) on particular deaths within our population. Currently these committees review deaths relating to:

- a) suicide
- b) perinatal and maternal mortality (related to childbirth)
- c) child and youth mortality
- d) peri-operative mortality
- e) family violence mortality.

The Child and Youth Mortality Review Committee (CYMRC) is one of the mortality review committees. I focussed on this review committee to ensure my scoping considered children and young people with intellectual disabilities who died. Staff from the Child and Youth Mortality Review Committee were therefore interviewed, and documents available on HQSC website reviewed.

The CYMRC's purpose is to review the lives and deaths of children and young people – aged between the ages of 28 days and 25 years with the aim of reducing preventable deaths of children and young people in New Zealand. The committee aims to understand how, why, when and where children and young people die.

Regional review committees and one national committee gather and confidentially manage a wide range of information pertinent to the child's life, health and well-being in reaching conclusions. This information can come from family, educational, recreational and social, as well as health sources. The review groups adopt a life-course approach, drawing a timeline about the child's life leading to the death. Information from such a process is then fed into the national database, which enables the National committee to analyse and report on general and specific trends. As such, the CYMRC national data collection represents a rich source of information potentially about children with intellectual disability who died.

It appears that CYMRC experiences similar challenges regarding coding of the information on Medical Certificates of Cause of Death that have been discussed earlier in this report. Despite drawing from holistic sources to understand the death, the subsequent recording follows medical-based codes for cause of death. The Committee has internal expertise to scrutinise and correct coding inaccuracies. Extracting circumstances involving a child with intellectual disability is again difficult, unless this has been specifically identified through the review process and recorded. Manual extraction through word searches similar to that used for coroners' reports may help identify the subjects of concern.

Although all deaths within its scope get reported to the CYMRC,⁸³ not all are reviewed by regional committees or the National committee. In fact, reviews occur for approximately 70% of all reported deaths. When deciding which child death to include in a review, the Committee prioritises children and young people of ethnic minority, and those living in inequitable situations. This latter criterion would conceivably draw children and young people with intellectual disability into the CYMRC's purview, but I could not confirm that having an intellectual disability was an inclusion criterion. Children and young people in more fluid living arrangements between family and others for periods may meet this inclusion criterion, for example, children who move in and out of respite or emergency care. It would certainly include children with intellectual disability who died while in foster care or respite funded by Oranga Tamariki.

The CYMRC clearly states it does not investigate deaths. Where concerns exist such that an investigation might be warranted, committees make recommendations and pose questions for others to follow through with. This approach stems from a deeply held principle that effective reviews must occur in a 'no-blame' culture.

CYMRC reviews nevertheless offer an opportunity to better understand the lives and deaths of young people with intellectual disability, whether they died at home, in care, or in hospital.

The CYMRC can conduct special reports on emerging or ongoing issues deemed to be of particular importance. In the past this has included special reports on sudden infant death, and every year there are reports specifically on child and youth suicide. Future options might include alcohol and other drug use, and possibly disability.

All deaths of children and young people while in hospital care go into the national minimum data set. The committee's distinction between hospital and community deaths was not found elsewhere, and it was unclear whether community deaths were treated as rigorously as hospital deaths in reviews. Families of children with significant health and disability support needs must navigate multiple hospitalisations as well as coordinate multiple health and disability services. This adds to the challenges for sharing and integrating information from records unlikely to record intellectual disability, regardless of the setting of the child's death.

DHB Mortality Review Committees

Some District Health Boards (DHBs) also conduct internal mortality reviews (such as the Canterbury and Southland DHB). I am unclear how these reviews might add to the picture of deaths relating to intellectual disability, given the small numbers likely reviewed by each.

These DHB processes may be more relevant for DHBs which provide inpatient services for people with intellectual disability – Capital Coast, Waikato, and Waitemata District Health Boards. Due to resource constraints, I was unable to identify how the findings from the DHB review committees are shared. Their existence adds to the complexity of extraction.

Office of the Ombudsman Review

In 2018, New Zealand's Chief Ombudsman announced his intention to investigate the role of the Ministry of Health in the collection, using and reporting of information about the deaths of people with intellectual disabilities. The investigation found that 267 deaths were reported to the Ministry in

⁸³ Most notified deaths come via Births Deaths and Marriages. Additional sources include Ministry of Health, DHBs, schools, and Oranga Tamariki.

a 2.5 year period, and identified a further 30 that should have been reported. It conducted a more in-depth review of a sample of 108 cases where people with intellectual disability had died in fulltime residential care across three regions of New Zealand. The Chief Ombudsman published his findings in July 2020.

The Office has a duty to monitor government performance of its obligations under the United Nations Convention on the Rights of Persons with Disabilities. It was triggered by notification of ongoing poor health outcomes.

Its primary purpose was to investigate the administrative conduct of one government agency in recording those deaths and see what lessons were drawn from those deaths, rather than to review the deaths per se. As such it cannot be directly compared to overseas death reviews of people with disabilities. Nevertheless, its analysis of information regarding the smaller sample of 108 provided a unique insight into how records, investigations and monitoring did or did not occur.

I believe this is the first independent review of deaths specific to disabled people in government-funded care report in New Zealand. It establishes a New Zealand precedent, and is a welcome addition to the otherwise scant picture within New Zealand.

Ministry of Health Reviews

The Ministry of Health Disability Directorate (and precursor departments) receives notifications of deaths of people with disabilities in care. The data from such a source can build knowledge not only on matters of relevance in the provision of disability support, but also the critical interface with the primary and secondary health system. It is the role of Ministry of Health to lead such work. As already indicated from the Chief Ombudsman's report, no such reviews have occurred. There have been no reviews using this rich source of data targeted to people whose health status is of such concern.

I note elsewhere the Ministry has accepted the recommendations from the Off the Record report, which include undertaking or commissioning regular reviews of deaths, led by the Ministry of Health. The Ministry has agreed to update the Chief Ombudsman on progress.

Internal Reviews by Service Providers

I am unaware if community disability support providers in New Zealand have shared publicly any internal reviews of deaths. It is more likely that providers have disseminated practice guidance consequent on individual investigations, for example on the safe management of choking.

International Reviews

In contrast to New Zealand, there are numerous international examples of one-off and sustained mortality reviews of people with intellectual disability. They usually review a cohort of deaths across a period of years, and are led by an independent statutory authority such as an Ombudsman, or an independent research body.

Some states in Australia have reviewed deaths of people in varying levels of care, subject to state definitions that require review (reviewable deaths).

In 2018, Victoria’s Disability Services Commissioner prepared its first progress report into 20 of the 103 deaths in care notified to it for the year 2017 to 2018.⁸⁴ This continued with another report into 100 deaths in the 2018 to 2019 year.

Queensland’s Office of Public Advocate reviewed the deaths of 73 people with intellectual disability in 2016.⁸⁵ This review has not been repeated.

In New South Wales, the Ombudsman took a more sustained approach to considering the circumstances of those who died in care, beginning in 2013, and reporting three-yearly since.⁸⁶ These reports provide a wealth of evidence that reflects international research. With each report cycle, the NSW Ombudsman has identified and commented on persisting patterns and provide guidance.

Western Australia’s government has not undertaken any such reviews. However, in 2012 their Law Reform Commission reviewed the state’s coronial processes⁸⁷ and noted the jurisdiction of the Coroner to investigate not only people held in custody but people held in care, specifically those with intellectual disability. The Law Reform Commission recommended a distinction between definitions of persons held in care and persons held in custody. Currently West Australia’s Department of Community Services, which oversees community disability residential services, draws from Victoria’s reviews for guidance on its own practices.⁸⁸

Australia’s system of disability support has been transformed with the introduction of the National Disability Insurance Scheme (NDIS). As a result, a new national body called the Quality and Safeguards Commission has been formed, and will take over the work programme of the NSW Ombudsman and possibly other states efforts as well.

In the United States, Massachusetts supported annual reviews for nine consecutive years, each prepared by an independent research body reporting to the state government.⁸⁹

The United Kingdom (UK) has had a number of campaigns to raise awareness of the vulnerabilities of people with intellectual disabilities who often face premature deaths. In 2004 a national community agency (MENCAP) ran the ‘Treat Me Right’ campaign to identify challenges in getting adequate health care for people with learning disabilities. This was followed in 2007 by a widely publicised report from MENCAP – a case study of six deaths called ‘Death by Indifference’. It led to a number of significant government responses, including two independent inquiries; the Michael Report in 2008⁹⁰, and another in 2012 called ‘Death by Indifference -74 deaths and counting’.

⁸⁴ Disability Services Commissioner (Vic). A review of disability service provision to people who have died 2017–18. Victoria Government: 2018

⁸⁵ Office of the Public Advocate (Qld) Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland - A systematic Advocacy Report. Queensland Government: 2016.

⁸⁶ NSW Ombudsman (2018) Report of Reviewable Deaths in 2014 and 2015, 2016 and 2017: Deaths of people with disability in residential care https://www.ombo.nsw.gov.au/data/assets/pdf_file/0006/58389/Report-of-Reviewable-Deaths-in-2014-2017.pdf

⁸⁷ Law Reform Commission of Western Australia – Review of Coronial Practice in Western Australia: Final Report (2012) https://lrc.justice.wa.gov.au/P/project_100.aspx

⁸⁸ Marion Hailes-MacDonald; Deputy Assistant Director General Disability Services Western Australia. Personal correspondence.

⁸⁹ Lauer E. Massachusetts Department of Developmental Services Annual Mortality Report 2002, 2003, 2004, 2005, 2006, 2007, 2008, 2009, 2010-11, 2012-13. <http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/newsroom/quality-assurance/mortality-reports.html>

⁹⁰ Michael J, Richardson A. ‘Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities’. Vol. 13, Tizard Learning Disability Review. 2008. p. 28–34.

As a result of greater public awareness and concern, the UK government then commissioned a substantial Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)⁹¹, which reported in 2013. Its recommendations then resulted in the National Health Service further funding a five-year project called the LeDeR project, led by Professor Pauline Heslop, to strengthen the strategic and systemic base for better understanding premature mortality. The LeDeR project has gained traction on a number of levels:

- The project team is partnering with the Royal College of General Practitioners on better recording of deaths on death certificates.
- Providers are using a consistent format for reporting the results of internal investigations into deaths to a central repository. The project team is already sharing lessons and common themes openly with disability providers and with health services.
- The LeDeR project is planning a national register of all deaths of people with learning disabilities.

These UK reviews have had an enduring effect on government attention to the issue, and the resulting LeDeR project has some implementation challenges. It remains to be seen if such focus translates to significant improvements in health outcomes for people with disabilities.

Families' involvement in investigations

Delays in getting answers to questions about a worrying death is hard for all parties involved, but especially for bereaved families and friends.

Julian (2016)⁹² reported on the shared experiences of families involved with investigations about the death of a family member. When investigations did occur (sometimes after significant lobbying by families), she reported there was little focus on answering families' questions about what had happened in the care of their loved one.

Julian later reviewed family involvement in death investigations across Australia, Canada, and New Zealand as part of her Winston Churchill Fellowship. Her 2020 report⁹³ noted the significant constraints and strains on bereaved families who may have questions or concerns about the circumstances of their family member's death.

A number of factors influence who requests, initiates and leads an investigation. Each type of investigative or review process that exists in New Zealand has a slightly different frame of reference, which can result in a similar deflection from the family's primary drive.

The Health and Disability Commissioner reported that individual circumstances affect the degree and nature of family involvement for investigations it undertakes. Families must be notified of the Commissioner's decision to act or not on preliminary assessments, investigations, findings, and onward referrals if family member is the complainant or meets the condition as "any person alleged to be aggrieved".

⁹¹ Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. 'Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)'. Bristol Norah Fry ... [Internet]. 2013;1–128. Available from: [https://rcpsych.ac.uk/pdf/Confidential Inquiry into premature deaths full report.pdf](https://rcpsych.ac.uk/pdf/Confidential%20Inquiry%20into%20premature%20deaths%20full%20report.pdf)

⁹² Julian G (2016) Family involvement in, and experience of, death investigations by the NHS, 13 December 2016 <http://www.georgejulian.co.uk/wpcontent/uploads/2016/12/FamilyInvolvementExperienceNHSDeathInvestigationsFinal.pdf>

⁹³ see footnote 5

Families are consulted about the decision of the Coroner. In many instances, family members also actively contribute to the coronial process with provision of critical information.

It appears the role of families appears to be primarily as a complainant or informant. However, we know that family members and disability service providers may have very different perspectives about the care provided.⁹⁴ In New Zealand, it was families raising concerns about the quality of disability services to the Ministry of Health, and those quality breaches that were the foundation for the 2018 'Putting People First' quality review.⁹⁵ Families can be the most powerful voice for people with profound intellectual disability and/or complex support needs. When health providers struggle to understand the expressions, will and preferences of people with complex communication challenges, family will become the interpreter.⁹⁶

The stated purpose of most investigations into deaths is to get a clear picture and share lessons for New Zealanders. Future work programmes need to include family perspectives in their own right, not just as complainants or caregivers with information.

Family involvement in reviews

There is potential for families to also be involved in Reviews, as occurs with Child and Youth Mortality Review processes, where their input could highlight common concerns from families. Families' input in CYMRC processes appears to be as a result of the holistic approach taken by those committees. Family participation and contribution is expected simply by virtue of their central relationship to the deceased child.

It appears that within New Zealand, the Mortality Review committees and investigative processes of the Coroners Court most align with the fundamental intent expressed by bereaved families – to understand and identify lessons from the death of a loved one.

11. SHARING LESSONS

How are lessons shared within New Zealand?

It was important to learn how agencies involved in mortality investigations and reviews drew lessons from their work and used this to influence policy and practice. Unfortunately, the enquiries revealed there are no publicly available mechanisms easily identified through which lessons are shared. Furthermore the separation of health and disability information means that there is no shared site.

Information was put in the public domain usually via agencies' websites. The problem with this passive approach is that people in the disability sector do not necessarily look at health websites and vice versa. Some websites are repositories of rich information, but we do not seem to have a means for unfamiliar parties to access their content, such as an information clearinghouse (as has been developed on family violence).

⁹⁴ Bossink, L. W., van der Putten, A. A., & Vlaskamp, C. 2017. Understanding low levels of physical activity in people with intellectual disabilities: A systematic review to identify barriers and facilitators. *Research in Developmental Disabilities*, 68, 95-110.

⁹⁵ Van Eden K. 2013. *Putting People First: A Review of Disability Support Services Performance and Quality Management Processes for Purchased Provider Services*. Wellington: Ministry of Health.

⁹⁶ Voices Project Report (2020) NZ Complex Care Group. <https://www.complexcaregroup.org.nz/wp-content/uploads/2020/07/Voices-Project-Report-EMAIL-VERSION.pdf>

Ministry of Health information

The Ministry of Health has a key role in informing the disability and health sectors and consumers of services about ways to promote better health outcomes. The Ministry largely uses its website to post publications on its health outcome work.⁹⁷ In the past this has included some brief case studies of innovative approaches to health support. With specific regard to mortality reporting, the Ministry indicated it had not shared any reports or analysis of information it had received with the disability sector through its regular forums or newsletters prior to the Chief Ombudsman's investigation.⁹⁸ The Chief Ombudsman has now recommended this begin and that the Ministry regularly report to the sector. This would be of great value if it was also accompanied by guidance on good practice.

In 2019, the Ministry strengthened its internal standard operating procedure (SOP) for collecting and using death reports from providers. This process is only applicable to deaths occurring in community residential care. Information from the Ministry's SOP has not been formally shared with the sector. Doing so in summary form would signal to the disability sector its commitment to working with the sector to improve health outcomes and mortality figures.

Coroners Court information

The Office of the Chief Coroner publishes selected findings on its website if a Coroner's report includes recommendations or is perceived to be of public interest. Other than reports deemed to be of public interest, recommendations consequent on a specific death mainly go only to the parties directly involved. The Court also has a small team available to assist with legal and research requests, and was very able to assist with my specific requests about coroners' reports on deaths of people with intellectual disability. It appears therefore that lessons from coronial processes might indeed be very helpful to providers of health and disability services, and there is a relatively easy access path. They would require collation and analysis to formats similar to the Recommendation Recaps currently used.

Health and Disability Commissioner (HDC) information

The HDC similarly uses its public website to post findings from investigations where it has found a breach of human rights. Its past practice has been to not name providers found to be in breach, but this has changed. The publicly available reports are not filtered by impairment type or by outcome (death near miss, or harm). It is necessary to manually search and extract investigation findings particular to death and intellectual disability. It would be valuable to lift lessons from the relevant reports to share them with the appropriate health and disability sectors, because they are so comprehensive.

Health Quality & Safety Commission (HQSC) and Mortality Review Committee information

Reports from the Child and Youth Mortality Review Committee (CYMRC) and the other mortality review committees of HQSC are published on the HQSC website. Generally these have been in the form of comprehensive annual data reports, but the mortality review committees are considering a move to more systematic and themed analyses.

Current annual reports are intended for use by District Health Boards, other health providers, and researchers. Their generic nature has meant they are largely unfamiliar to providers of disability support, even those working solely with children and young persons. As such, the proposal to shift to

⁹⁷ Innovative Methods of Providing Health Services for People with Intellectual Disability: A review of the literature. 2013. Wellington: Ministry of Health.

Providing Health Services for People with Intellectual Disability: Case Studies of programmes and tools used in New Zealand 2013. Wellington: Ministry of Health.

⁹⁸ The Ministry updated the sector on its response to the Chief Ombudsman's report in newsletter 31 July 2020.

themed analyses from mortality review committees may aid sharing information with those significantly involved in the lives of children with intellectual disability and complex health needs.

As discussed already, few providers of disability support engage in the Adverse Events notification processes managed by HQSC. These are designed to identify practice improvements. The Chief Ombudsman's report has recommended action to increase disability provider compliance with the adverse events register, which is currently not mandatory. This presents another opportunity for health and disability professionals to learn from deaths or near misses, but the current process has a significant medical bias given its background. It is likely that compliance would be helped by consultation and collaboration between the HQSC, disability provider networks, disabled persons organisations, and the Ministry of Health to reflect the broader scope of disability support and the context and culture of the disability sector.

The Mortality review committees overseen by HQSC operate strictly within a no-blame approach to maximise the quality of information that might reveal lessons. This seems an obvious and desirable approach. But it can be difficult to maintain in environments of low trust, or where legislative mandate requires investigation of breaches or attribution of fault. Additional problems with openness arise when the funding body is also the one investigating or reviewing deaths.

Information from disability support providers

Disability service providers also generate opportunities for sharing information. The New Zealand Disability Support Network (NZDSN) is a peak membership body of approximately 160 disability providers across New Zealand. It hosts forums and conferences for the exchange of information. The Australasian Society for Intellectual Disability: Research to Practice (ASID) also hosts conferences attended by disability providers and researchers. As past public criticisms and prosecutions have created a culture of fear of exposure, it is rare for death to be a topic covered within these information exchanges.⁹⁹ Again these exchange forums have a limited audience, with families and health providers rarely present, meaning that lessons are not always shared with the right audience.

Current mechanisms to investigate and review deaths (for example, through the Coroners Court and HDC) are often complex and undertaken carefully. This usually means they take a long time. Families, health and disability providers needing to improve or change their practices may get information from these investigative processes some considerable time after the fact, and only if they were a significant party to it.

Given these agencies deal with some of the most comprehensive scrutiny into deaths involving people with intellectual disability, it would be helpful to consider ways to make their insights accessible to a wider audience.

Already, it is possible to identify some circumstances known to contribute to premature and worrying deaths; epilepsy, late detection of pneumonia and other infections, choking from aspiration of food and drink, drowning related to lack of supervision. I found no examples of publicly shared practice guidance from New Zealand providers, though I understand some providers have developed resources for internal use.

⁹⁹ Brandford S. "Last Days of Life in a Disability Service – a snapshot", unpublished conference presentation ASID Conference, Sydney Australia 2013.

How are lessons shared overseas?

The LeDeR project from the UK has already been described in the Mortality Review section. It is the first national programme dedicated to sharing lessons to improve life expectancy. With each annual report, the project team contributes to a Repository of key findings and recommendations from individual case reviews, available on its website.¹⁰⁰ In its analysis of deaths in 2018 to 2019, six themes emerged:

1. Better communication within and between organisations, for example, information sharing, using hospital passports, disability identification flags on medical records
2. Greater adherence to legislation and guidance
3. Better communication with families, carers and people with learning disabilities
4. Improving systems-related and interface issues
5. Improving quality of direct care provided
6. Investing in professional practice, such as attitude and values, health-specific training.

The annual reports published by the LeDeR project include best practice examples – such as strong inter-agency cooperation and examples of providers making reasonable adjustments – as well as practices of concern. The LeDeR project has shared practical guidance on end of life care, ‘Do Not Resuscitate’ orders, and the value of hospital passports to inpatient services.

Another good example of investment in sharing lessons comes from some Australian states. The New South Wales government has conducted reviews since 2012, and more recently published brief fact sheets on a range of topics for disability support providers and health providers. These include recommendations about smoking, obesity and other lifestyle risks, breathing, swallowing and choking risks, information for General Practitioners, and information for staff of disability services.

More recently, the Quality and Safeguards Commission of NDIS commissioned a scoping review to provide a national baseline picture of death trends and related factors.¹⁰¹ That report collated findings from the various state reviews and has produced guidance on ways to reduce preventable deaths. West Australian state government reports it uses this report and brief guidance tools from NSW’s Ombudsman in its work. Its content provides an excellent base for New Zealand to follow.

Queensland’s 2016 review of 73 deaths was led by an independent body at the state government’s request, but it appears that this work has not been replicated. Nor has the state government committed appropriate resources to implement its recommendations.

Are overseas lessons applicable in NZ?

Given the paucity of reviews within New Zealand, the best opportunity right now for us may be to collate and share lessons from overseas. Common features arise in both New Zealand and overseas death reports, so it seems wise to include experiences from overseas to guide practice here.

The invisibility of people with disability is further compounded when they live with other disadvantages as well. Considerable work is underway in New Zealand to address health inequities for

¹⁰⁰ <http://www.bristol.ac.uk/media-library/sites/sps/leder/Repository%20Analysis%202018%20-%202019.pdf>

¹⁰¹ A scoping review of causes and contributors to deaths of people with disability in Australia (2013-2019): Findings Salomon. C and Trollor. J. Department of Developmental Disability Neuropsychiatry UNSW August 19th 2019 <https://www.ndiscommission.gov.au/document/1881>

Māori and Pasifika¹⁰², and this would be a sound platform for future efforts if extended to include New Zealanders living with intellectual disability.

Overseas examples that have resulted in greater visibility of death matters have been led and overseen by independent bodies, drawing from multiple disciplines and perspectives. Common to the positive UK and Australian experiences from reviews are the following:

- Government commitment to sustained focus - beyond time-limited projects
- Independently led collaborations with health and academic expertise to ensure the review work is methodologically rigorous.

The work of the Ombudsman in NSW was sustained for some years, enabling patterns and trends to become more visible. It resulted in the publication of the fact sheets on preventing deaths of people with intellectual disabilities in care listed above. In contrast, Queensland did not commit resources to the recommendations from its review in 2012, and no progress has been reported.

The LeDeR project in the UK identified instances where a deceased person had a 'Do Not Resuscitate' Order where the listed reason for the Order was having a learning disability or Down Syndrome. As a result of this and ensuing public awareness,¹⁰³ the Project team has made appropriate recommendations to stop such discriminatory practices. This lesson is applicable and equally pertinent to New Zealand (with minor adjustments to reflect domestic legislation).

The benefits of sustained investment and independent leadership are evident in the above review projects. Commissioning substantive work such as this will require the skills and experience of persons outside the public sector. Reviews such as those undertaken overseas require a range of highly skilled professionals working collaboratively, and in a culture that maximises open information exchange. It would seem helpful to ensure this occurs in New Zealand through agencies that are not associated with contracting and funding, or with ascribing fault. The Ministry of Health's Disability Directorate has acknowledged challenges in maintaining some work programmes given its substantive sector transformation work. While a critical contributor to future work, it may not be best placed currently to lead it.

The Chief Ombudsman has suggested the HQSC become more actively involved with the disability sector, since it undertakes this role in the context of physical health and mental health already. This indeed presents an opportunity for reducing the discrete approaches currently within New Zealand and for sharing lessons across health and disability sectors. It appears that some within the disability sector including consumer groups are not keen to see disability matters more subsumed under health sector policies and provisions than they already are, based on feedback about the proposed review of the Health and Disability sector. Some bridge building to identify common ground will be necessary if the Chief Ombudsman's suggestion is to bear fruit.

12. WHAT NEXT?

When I started this work, I felt strongly the absence of data on how many people with intellectual disability die in New Zealand, or when and where they die. Because of their invisibility within population and health records, it becomes significantly harder to understand why they die, and then to do anything about that.

¹⁰² See footnote 21.

¹⁰³ "Doctors warned disability or Down's no reason not to resuscitate patients" Sunday Times [London, England], 12 May, 2019, p5. Gale Document Number GALE|A585142302

In writing this report, I found my concerns about the lack of data were justified. However, there is opportunity and willingness to improve our efforts. This project presents a strong case to press for more urgent progress on disaggregation of disability data.

In the meantime, a number of initiatives could be commissioned to make better use the information we already have.

Many of those contacted for this project identified how they could monitor premature deaths among people with intellectual disability more closely. Each idea presents a step closer to solving the problems outlined and adding to our knowledge base.

- The Child and Youth Mortality Review Committee has the capacity to undertake specific reports, perhaps on deaths of children with disability. This would be a helpful contribution.
- The Health Quality & Safety Commission (HQSC) might partner with others to disseminate information across and between the health and disability sectors. This would include drawing from local and international sources to offer fact sheets, practice guidance and resources.
- The Chief Coroner has discretionary authority to report on matters it deems useful (such as fatalities in the mountains, or fatalities related to methamphetamine use). To date it has not exercised that discretion specific to premature deaths of people with intellectual disability, but could be offered suggestions for closer attention, for example, on matters related to late diagnosis of pneumonia or infections; low use of health passports for people with disability in hospital; or the contribution of high polypharmacy rates¹⁰⁴ on premature deaths.
- Real traction will come when these individual actions become part of a coordinated response.

Generate a culture of openness not blame. A key to stepping forward positively will be the way we create a constructive culture of enquiry. Bereaved families want open and honest scrutiny when someone they love dies, so it counted for something of value for others in the future. This desire is not unique to families of disabled people. Health providers and disability providers also want to be able to reflect on their practices in an open and honest way. Disabled persons organisations lobbied hard to see poor health outcomes prioritised in the government's Disability Action Plan. Changes will be more likely achieved when there have been safe forums for airing perspectives, for challenging misconceptions, and for common ground to emerge.

Build reciprocal knowledge between the health and disability sectors. Adjust practice accordingly. Commit disability support providers and funders, as well as health professionals involved in health pathways to respond promptly and appropriately to what they find. Parallel work would involve educating disability support personnel so they can identify changes in a person's health status and effectively support access to medical advice. It would also involve training health professionals about how they can be inclusive in their attitude and practice when someone with an intellectual disability needs health support. Establishing a clearing house of educational resources and practice guidance applicable to sector audiences would be a step forward.

Develop an independent national death review system. The Chief Ombudsman has introduced the idea of New Zealand developing a National Review system, as has been demonstrated/done in England with the LeDeR programme. In Australia, Professor Trollor has recommended a national register of deaths particular to intellectual disability, and the Quality and Safeguards Commission has published methodological guidance on conducting Death Reviews across Australian states. From the UK, lessons about what has enabled and hindered death reviews there would prove very useful for New Zealand consideration. Combined, these initiatives would serve as useful guides for New Zealand as we all

¹⁰⁴ People with intellectual disabilities are commonly prescribed high levels of multiple medications.

consider the Chief Ombudsman's recommendation. While directed to the Ministry of Health, others across our health and disability sectors will have valuable contributions for discussion and implementation. Sustained commitment will however be needed to reap real benefit.

Coordinating a national review system in New Zealand will require liaison between a number of organisational and public sector interfaces. The Chief Ombudsman has the opportunity in its oversight of United Nations Convention obligations to drive action across government agencies on data integration and possibly on repeated reviews to identify trends. It seems preferable to set up an independent body to lead this work in line with overseas models. This might even be a body separate from the government, such as an academic or research institution.

Support levers for change Historically, change has come when people with disability and families have mobilised. As discussed later in these concluding comments, engaging with advocacy networks will likely be helpful.

Change to health services can be encouraged by highlighting economic impacts and opportunities. People with intellectual disability are high users of health services, including high cost components such as pharmaceuticals, primary health, and emergency services. Overseas initiatives suggest that partnered approaches with disability researchers and providers may ameliorate some costs.

Partner with advocacy groups. Disability advocacy has been driven in the past by families. It was family who sought dignity for those who died at Tokanui Hospital and were buried in unmarked graves in what is now a paddock. Families remain critical supports and sometimes advocates for their family members with intellectual disability. For those with profound intellectual disability and/or complex support needs, families can be the most powerful voice to support the will and preferences of those who others struggle to understand.¹⁰⁵

Significant advocacy already comes from government agencies committed to better lives for people with intellectual disability, such as the Human Rights Commission, the Office for Disability Issues, the Health and Disability Commission, and the Office of the Ombudsman.

But people with intellectual disability are also strident advocates on matters about their own lives, and must be included in efforts to reduce their premature deaths. I anticipate the real momentum to address the so-claimed apathy within New Zealand will come from families and from people with intellectual disability. They seek changes to give all a fair and just chance of a good and long life.

13. LIMITATIONS

I have comprehensively explored some aspects of the complex mechanisms that currently inform our understandings of mortality. I chose matters I felt would illuminate both the complexities and the opportunities for us in New Zealand. I was unaware till late in this work of the occasional but significant role that WorkSafe New Zealand plays in some investigations of deaths within disability service settings. I did not enquire with that agency directly, but its mandate may impact on the openness of investigative processes.

In keeping within the constraints of a scoping project, this report does not draw from the depth of expertise available to use statistical and population data more effectively. This would strengthen future work.

¹⁰⁵ Voices Project Report (2020) NZ Complex Care Group. <https://www.complexcaregroup.org.nz/wp-content/uploads/2020/07/Voices-Project-Report-EMAIL-VERSION.pdf>

Many people who live with other disabilities or mental illness have an equal interest and concern about the matters canvassed by this report. I have focussed on the challenges and opportunities for people with intellectual disability alone because of my experience and expertise. I recognise a similar limitation with regard to Tangata whenua¹⁰⁶, for whom this issue, without question, deserves comprehensive attention from a te Ao Māori perspective.¹⁰⁷

I did not directly canvas views from disability advocacy networks for this project, although I know they share a longstanding interest in the wider goal of improving health outcomes for people with intellectual disability. Among these are Nga Tangata Tuatahi - People First New Zealand, Disabled Persons Assembly New Zealand, the Complex Care Group, Parent to Parent, the Human Rights Commission, and the Office for Disability Issues.

I believe a formal consumer and family advisory group would significantly enrich future work, and facilitate partnered approaches.

I hope this report encourages contributors and stakeholders to address the limitations inherent in a scoping report, and commit to joint work to strengthen our knowledge and practice in the better interests of children and adults with intellectual disability and their families.

14. CONCLUSIONS

My report describes how the deaths of people with intellectual disability are collected, investigated, and reviewed in New Zealand. It is based on broad consultation across a variety of sources, including international and New Zealand research, and has canvassed the concerns of family and advocates. This report identifies opportunities that exist in New Zealand to extract knowledge from various sources, and to improve attitudes and practices here.

I conclude that deaths of people with intellectual disability are not subject to the systematic scrutiny one should expect, given the wealth of research indicating their poor health outcomes and reduced life expectancy. Their deaths are largely invisible. Some of this appears to be because mortality data collections and health utilisation data does not flag a person's disability.

Small steps have begun in meeting our obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to disaggregate disability information from population through the upcoming Health Survey. To do this, we need to navigate a path through the complexities of disability in the context of health whereby deaths are coded using standardised medical diagnostic conventions. This would enable us to extract information that would inform us better about risks and vulnerabilities, and measure the effectiveness of interventions.

Despite people with intellectual disability living in a range of care situations funded by the state, current mortality research tends to focus excessively on deaths within a narrow range of situations. Providers of residential care are currently the only contacted care providers obliged to report deaths to the Ministry of Health. This compounds the invisibility of populations. The shape of disability support continues to appropriately change from the more visible placements in institutions or group homes towards a greater variety of settings. As more people purchase support directly from government funders, it raises the question about the circumstances in which the state might monitor

¹⁰⁶ Māori, people born of the land.

¹⁰⁷ A Māori world view, incorporating the language, protocols and customs, and the Treaty of Waitangi.

deaths and collect and use information,¹⁰⁸ given that so many are reliant on others for access to good support and health care.

It is currently difficult to extract investigation and review material. Reports are often sourced through websites, assuming people know where to look, or shared within narrow sectors of health and disability systems. This report has identified opportunities among existing agencies to undertake more focussed reporting on people with intellectual disability who have died. I encourage this. It would be wise, however, to move beyond piecemeal actions and consider a collaborative programme and leadership group to collate information and translate it into changed practices.

The Chief Ombudsman's 2020 report 'Off the Record' recommended setting up a national review system, which would represent a significant improvement on our current situation. It could complement similar initiatives overseas, but only if it facilitates honest debate on difficult topics and creates an open environment to share both good and poor practice relevant to improving health. I welcome wider engagement about how an independent system of death reviews might operate, and how a clearinghouse of research and practice guidance might advance our collective efforts.

Bereaved families and people with intellectual disability are currently on the periphery of processes of investigation or review unless in the role of complainant or informant. They need to become more central as partners, so that their perspective contributes to future policy and structures for overseeing mortality work. Families largely want their family member to be acknowledged in death and for any failings to become a vehicle for improvements in the future – that their lives and their deaths counted for something.

¹⁰⁸ Ministry officials have expressed differing views on whether they have a duty to enquire into the deaths of people in residential care, arguing this is 'their own home'. Cited in 'Off the Record' (page 84).

15. APPENDICES

Appendix 1: Estimating how many people with intellectual disability die each year.

Path 1: Every three years, the Ministry of Health carries out a demographic survey of those who use its disability support services (DSS). Reports from the surveys – that are based on the first nine months of the year – indicate patterns of service use by its clients, almost half of whom are people with intellectual disability.

The 2013 Demographics Survey Report was the last time the Ministry of Health reported the numbers of people who died within its sample period. As such, one can get a crude estimate of the death rate for a specific population who fit within the definition of being in care.

In its 2013 report, it noted 298 deaths amongst all types of disability groups over the nine-month period, extrapolated to 372 deaths in 12 months.

As half of that report sample were people with intellectual disability, a crude estimate is that 185 may have been people with intellectual disability. By the time the next Demographic Survey was reported in 2016, there had been an 8.7% increase in the numbers of New Zealanders using Disability Support Services. That report did not report on mortality. But on the basis of the overall increase (8.7%), in 2016 we might have expected 201 deaths of people with intellectual disability.

Path 2: Using population prevalence information, we run into even murkier water as there are few accurate estimates of the prevalence of Intellectual Disability in the New Zealand population. Internationally, the prevalence estimates are often 2% of the total population. In 2011, the Ministry of Health published research on the Health Indicators for People with Intellectual Disabilities. That research drew from data on health utilisation across New Zealand's entire population. It reported that 0.7% of its population sample in 2010 identified as having an intellectual disability (n=31,847).

New Zealand's crude death rate (using 2016 figures) is reported to be 6.81/1000 people. Using the sample subset from the Health Indicators report, this death rate would translate to an estimated 216.88 (rounded to 217deaths) per year [$31847 \times 0.00681=216.88$].

Path 3: This data source comes from the investigation by the Chief Ombudsman 2020. The Chief Ombudsman's report noted that a total of 267 reported to Ministry of Health across a 2.5 year period.¹⁰⁹ In addition, he identified a further 30 deaths occurring within that period, but not notified to the Ministry, increasing the total to 297. Assuming a constant rate of death across these 30 months, this would see 118.8 deaths in a 12 month period (rounded to 119).

¹⁰⁹ His investigation largely focussed on a sample of 108 receiving full-time residential support in the Auckland, Wellington, and Canterbury regions. A further 159 outside those selected regions were reported, but their details not verified through this investigative process.

Appendix 2: Description of disability support arrangements providing 'care'

Community residential care

Community residential care describes supported accommodation and living support for people with disability in group homes and residential facilities. It includes accommodation and paid staff support across the day and night, to varying intensity.¹¹⁰ The majority of people supported through group homes are adults with intellectual disability.¹¹¹ A variation of community residential care is called Choices in Community Living. In this model, people in group homes are encouraged to have more choice and control within the facility (e.g. who supports them, who they live with, routines of the service).

Regional Intellectual Disability Supported Accommodation Services (RIDSAS) and Regional Intellectual Disability Secure Services (RIDSS)

This refers to supported accommodation for people, including residential care that fits within court-mandated level of supervision for people subject to the of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act). RIDSAS contracts are held by community-based providers, and RIDSS contracts are held by selected District Health Boards for the provision of secure inpatient care. The Ministry of Health Demographics report¹¹² 2016 indicated 244 people with intellectual disability were in such care services, under the High and Complex Framework.¹¹³

Aged care facilities

The Ministry of Health (MOH) also reports that a small number of 'under-age' people with intellectual disability live in aged care services which are funded through contracts with District Health Boards. They will likely receive care in similar volume and type to those in group homes above, albeit in larger congregate care settings. Few of those in such care arrangements will be so through court-mandated provisions such as the Protection of Personal and Property Rights Act.

Respite Care

The Ministry of Health (and also Oranga Tamariki) funds short-term respite care for children and young persons who usually live with their families. This respite care can be provided through a staffed facility, or by arrangement with vetted alternative caregiving families. Respite care does not involve any transfer of legal custody from families, but can place daily care responsibilities to a provider of respite for periods of days or weeks.

¹¹⁰Health and Disability Services (Safety) Act 2001. S.4 Residential disability care means residential care provided in any premises for 5 or more people with an intellectual, physical, psychiatric, or sensory disability (or a combination of 2 or more) to help them function independently

¹¹¹Based on 2017 Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services as at September 2016

¹¹²Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services as at September 2016; NB Where a Client recorded two principal disabilities, this report used only the first one

¹¹³High and Complex Framework is a range of services that support the operation of the IDCCR Act and provide services for people subject to compulsory care orders.