



UPHOLDING THE RIGHT TO LIFE AND HEALTH

Safeguarding the health of NDIS
participants living in residential care

Mary Burgess – Public Advocate, Queensland

The United Nations *Convention on the Rights of Persons with Disabilities* recognises that people with disability have the right to the enjoyment of the highest attainable standard of living, on an equal basis with others



The Public Advocate



- Statutory appointment under the *Guardianship and Administration Act 2000 (Qld)*
- Role is to undertake systemic advocacy to protect the rights and interests of people with impaired decision-making capacity
- Powers include:
 - Right to all information necessary to monitor and review the delivery of services and facilities to those people
 - Intervene in legal proceedings involving the protection of the rights or interests of people with impaired capacity
 - Make reports about systemic matters that must be tabled in the Parliament

The 2016 Review of Deaths in Care



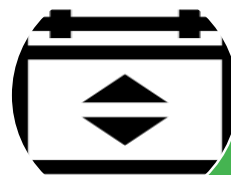
- The first systemic review of deaths of people with disability in care in Queensland
- Focused on the deaths in care of people with disability in Queensland from 2009 to 2014
- 73 cases examined by an Advisory Panel:
 - Heads of government agencies
 - Medical practitioners with expertise in the health care of people with intellectual disabilities
- Files provided by the State Coroner and various relevant Agencies

Key Findings



Place of death

- 58% hospital
- 42% home
- 62% died during the night



Age at death

- Male median age 53
- 25 years younger than general population
- Female median age 49
- 36 years younger than general population



Ethnicity

- 11% ATSI
- 1 Pacific Islander



Gender

- 70% male
- 30% female



All had an intellectual or cognitive disability

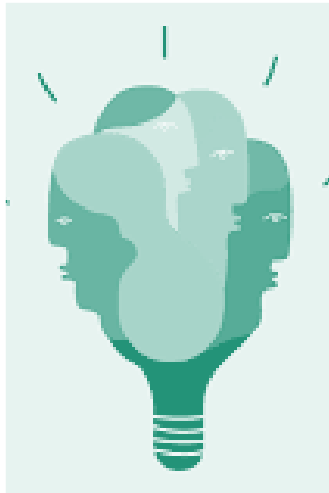
Other disabilities included epilepsy, autism, down syndrome and cerebral palsy

Key Findings



Main Causes of Death

- Respiratory Diseases (34%)
- Circulatory System Diseases (22%)
- Diseases of the Nervous System (11%)
- Cancers (10%)
- External causes – choking and food aspiration (8%)



Advisory Group Findings

- 59% of deaths were unexpected
- 53% were potentially AVOIDABLE

Recommendations



Health practice and standards

- Frameworks for improved health care including setting minimum standards, best practice and performance expectations, education and support for medical staff

Leading causes of death

- Detailed recommendations addressing individual health conditions including; respiratory disease, epilepsy, circulatory system diseases, cancer, dysphagia and the use of psychotropic medication

Disability practice standards

- Recommended NDIS code of conduct and registration/accreditation requirements include minimum standards in relation to health management, risk management,

Governance and accountability

- Recommended regular systemic reviews and reports to Parliament to monitor performance

Actions since 2016 - Government



- Full Commonwealth roll out of the NDIS Scheme
 - No or limited funding for health related supports included in plans until late 2019
- Whole of State government response to the review released in January 2019
- Two new initiatives from Queensland Health
 - Julian's Key Health Passport
 - App to assist people with disability communicate with health care professionals in settings like hospitals
 - Communicates:
 - Things you must know about me
 - Things that are useful to know about me
 - My likes and dislikes
 - Encouragement of all Hospital and Health Services to develop Disability Access Plans
- Continuation of funding for the development of Comprehensive Health Assessment Plans in 2019-20

Actions since 2016 - Government



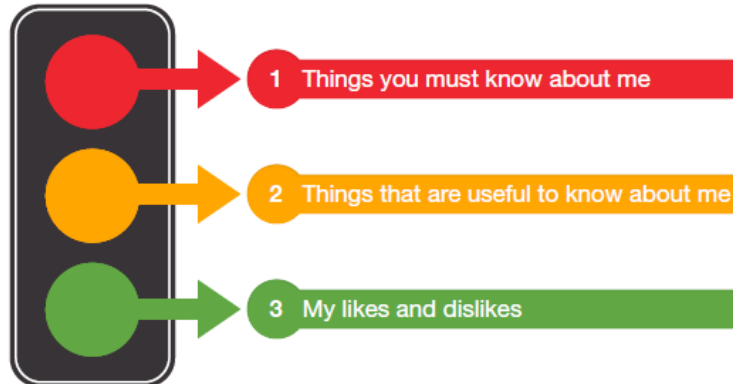
This is my Health Passport

Capturing important information about me and my health care needs.

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me. It needs to be available to staff and a copy should be put in my notes.

My name is:

Nursing and medical staff please look at my passport before you do any interventions with me.



I am NDIS registered:

Date completed:

Completed by:

This document belongs to me. Please return it to me or my carer.



Things you must know about me



My communications style

*I can usually communicate verbally?**

☐

Yes

☐

No

Please click one

This helps me to talk to you

☐

My communication system
(If yes, please name the system in other)

☐

Symbols

☐

Pictures

☐

Gesturing

☐

Facial expressions

☐

Simple words

☐

When you wait for me to respond

☐

My supporter/carers

☐

Other

This is what helps me to understand you

☐

Short plain sentences

☐

Simple words

☐

Concrete examples

☐

Diagrams or pictures

☐

Checking to see if I understand

☐

Asking me to explain it

☐

Asking my supporter/carers to explain it to me

☐

Using real objects

☐

Giving me a demonstration

Please communicate with me by

☐

Speaking directly to me

☐

Taking time to tell me

☐

Waiting for me to respond

☐

Writing down notes in my care plan

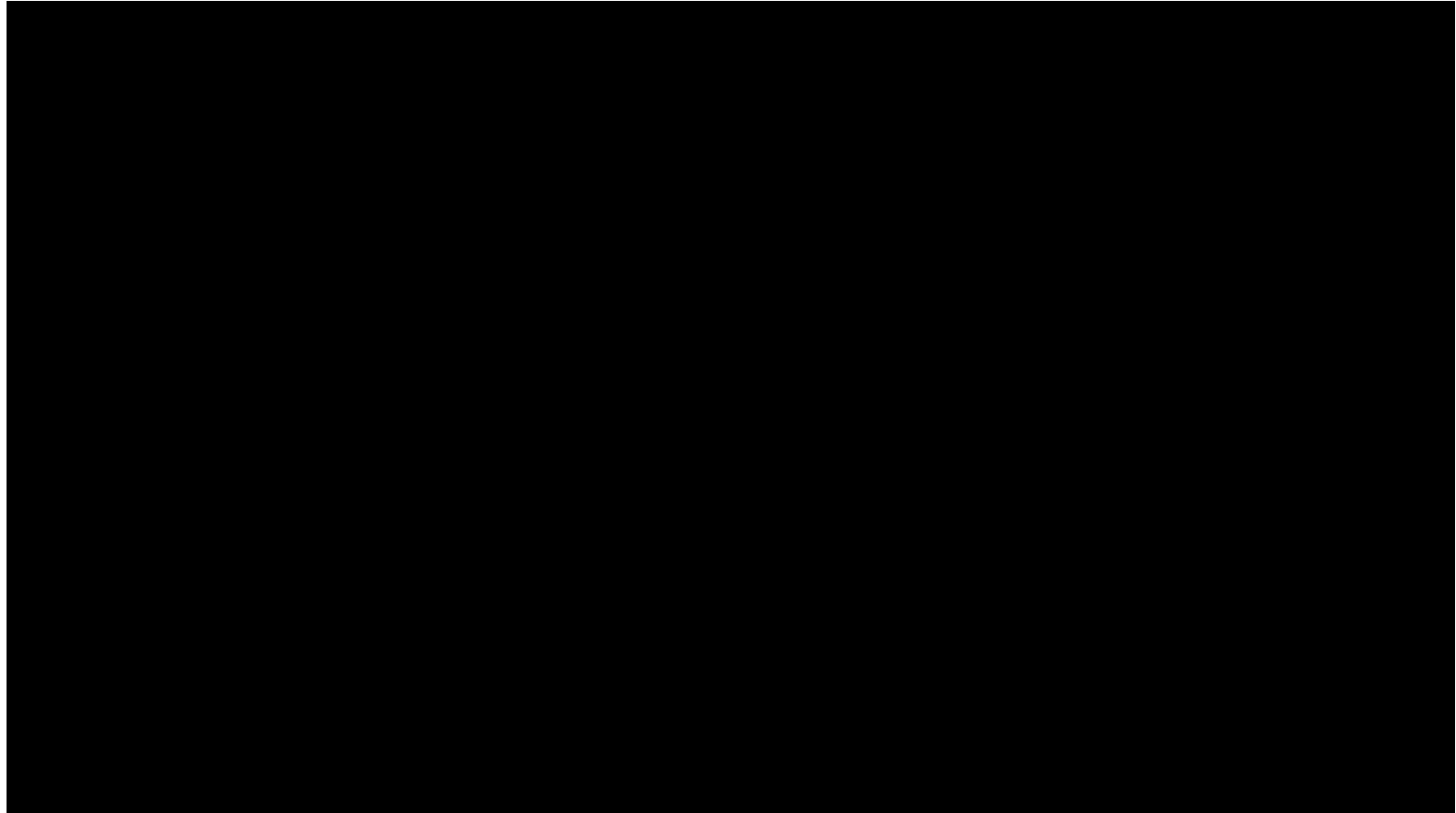
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Knowing I cannot talk but can hear and understand

Actions since 2016 - Advocacy



- Council for Intellectual Disability (CID) 'Hard to Swallow' campaign
 - Highlighted the needs of people with dysphagia and the lack of health related supports provided in NDIS plans



Actions since 2016 - Advocacy



- The Our Health Counts Campaign – End Disability Discrimination was also conducted in 2019 by CID, in conjunction with Inclusion Australia, the University of NSW, Down Syndrome Australia and the Australian Association of Developmental Disability Medicine



End Deadly Disability Discrimination



Our health counts

Up to half the deaths of people with intellectual disability are preventable – let's fix this

Take action: www.nswcid.org.au/ourhealthcounts



Inclusion Australia (NCID)
enjoy health - representing nationally - connecting globally



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The facts

Up to half the deaths of people with intellectual disability are preventable.

People with intellectual disability die 27 years earlier than the general population.

There are over 450,000 people with intellectual disability in Australia. Together with their families they number over 2 million.

Why is this happening?

Health professionals face challenges communicating with and treating people with intellectual disability.

"I've witnessed my brother be overtested, overmedicated and misdiagnosed because of a lack of health practitioners with experience in working with people who have an intellectual disability."
Annette

The solution

1. Leadership on this issue from the Australian Government.
2. Build and pilot curriculum content on the health needs of people with intellectual disability in university medical and nursing courses.
3. Fund 90 intellectual disability health professionals around Australia as an information resource for GPs and to help people with intellectual disability get the right health care.
4. A national inquiry into how to make the health system work for people with intellectual disability.

How you can help

- Visit our website www.nswcid.org.au/ourhealthcounts
- Sign our petition
- Download posters and flyers to distribute
- Find guides to help you phone, email and meet with your Federal MP
- Contact our Advocacy team at advocacy@nswcid.org.au
- Follow us and share our campaign on [Facebook](#) [Twitter](#) [Instagram](#)

End
Deadly
Disability
Discrimination



Actions since 2016 - Advocacy



- **2019 Queensland Roundtable: Health and Intellectual Disability**
 - Joint initiative of a number of key state and national advocacy organisations
 - More than 80 delegates from a diverse range of lived experiences of disability and health, disability, community, advocacy and rights and justice sectors
 - Allowed for the sharing of statistics and stories, further impetus for addressing identified issues
 - A family who shared their hospital experience with their son were later interviewed on ABC's 7.30 program to highlight issues associated with the health outcomes for people with disability entering hospital with serious, but treatable, conditions

Results



- In June 2019, the Disability Reform Council announced the **extension of NDIS funding** to now include disability health related supports
- NDIS will now fund disability health related supports in plans;
 - Provision of disability-related health supports by disability support workers after appropriate training
 - Allied health assessment, planning and the provision of, or training of disability support workers in the provision of, disability-related health supports
 - Assessment, planning and the provision of disability-related health support by nurses or training of support workers to deliver these services
 - Consumables related to disability-related health supports
 - Assistive technology related to disability-related health supports

Results



- In October 2019, the Federal Health Minister hosted a Roundtable on the Health of People with Intellectual Disability as a result of the 'Our Health Counts' campaign from the Council for Intellectual Disability (CID) and other advocacy initiatives
- Outcomes from this Roundtable included:
 - A commitment to the development of a National Roadmap for improving health services for people with intellectual disability
 - The Roadmap will be implemented from 2020 as part of the 10 Year Primary Health Care Plan
 - Focus on improving the skills and capacity of GPs, improved coordination between the health sector and education sectors to improve GP and nurse training, assistance for families to navigate the health care system
 - The Roundtable will re-convene in February 2020 to further discuss the development of the roadmap

However...



- It appears that;
 - The divide between Federal and State health services and the NDIS remains
 - There has been a gradual shift in responsibility for the treatment of people with complex and chronic health conditions from the Queensland Government to individual NDIS service providers. This can lead to;
 - Unrealistic expectations being placed on disability support workers
 - A lack of 'touchpoints' within the systems and
 - Risks in relation to the provision of proactive and pre-emptive health care
- There's also evidence indicating that health care for people with disability remains a critical concern in Queensland;
 - In 2018-19, 9% of all issues raised by community visitors from the Office of the Public Guardian related to health care needs – 207 issues related to health care in total
 - Figures released in January 2020 revealed that 270 Queenslanders with disability died whilst waiting for an NDIS package between July 2016 and September 2019

However...

- The situation is much the same across Australia.
- Deaths in NSW in 2014-2017 of people with disability in residential care:



Major gaps in life expectancy when compared with the general population

People in disability services
died at least **25 years earlier**

-25 years

People in assisted boarding houses
died around **20 years earlier.**

-20 years

Most of the deaths were **unexpected** and from **natural causes.**



Respiratory diseases
were the leading contributory
cause of death of people
in disability services



Circulatory diseases
were the leading contributory
cause of death of people in
assisted boarding houses.

However...

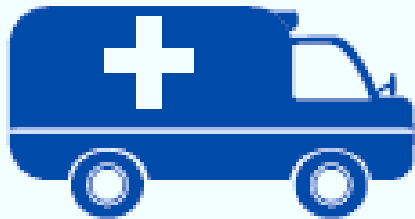
- The recommendations made in NSW are also similar:



Our reviews of **preventable deaths** highlight the need for concerted action to:

Identify illness or injury and take swift action to obtain urgent medical assistance

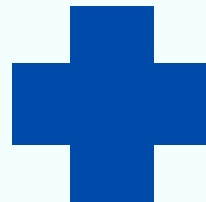
Improve access to preventive health services and supports - particularly for smoking, obesity and other lifestyle risks



Identify and effectively manage breathing, swallowing and choking risks

Ensure that treatment limitation decisions are informed and not based on perceived quality of life

Provide an effective first aid response



Improve support and coordination of care in hospital



Report 'near misses' and take action to prevent recurrence and death

Provide behaviour and other support to help to minimise aversion and resistance to health services and treatment



Reduce risks associated with medication - including medication errors and unsafe storage

The challenges



- The Public Advocate will continue to monitor and advocate for improved health services and health service co-ordination for Queenslanders with impaired decision making capacity
- The following needs to be implemented, at a minimum;
- **Nationally**
 - Medical and nursing degrees should include specific training on the health needs of people with disability
 - NDIS Plans should;
 - acknowledge **complex health issues** and incorporate the disability supports necessary to address health care needs, provide for adequate coordination of essential health care supports, and support attendance at medical and therapeutic appointments and
 - include actions to improve the **integration and communication** between mainstream health services, registered NDIS service providers, and other disability support services to ensure people with disability with complex health conditions are accessing the health services they need

The challenges



- In Queensland
 - People with disability who have complex health conditions need **individual health care plans** that are reviewed annually and used to inform the NDIS supports required to adequately coordinate access to health care
 - There should be regular systemic **reviews of deaths of people with disability in care**, which focus on the real and necessary changes required to improve health and longevity outcomes for people with disability
 - Funding should be provided to **pilot projects** that:
 - demonstrate best practice in coordination between health care providers and disability service providers
 - support improved training for health and disability workers about appropriate care for people with disability with complex health condition

Over to you...



- I want to hear from you
 - How do you feel about the NDIS changes – overwhelmed or relieved?
 - Are the new health related supports provided by the NDIS “enough”?
 - How do they work on the ground?
 - How do they integrate with state based health services?
 - Are there still gaps and challenges?
 - Are system changes still required to improve overall health outcomes?
- As the Public Advocate is not a direct service provider I rely on people like you sharing your stories and lived experiences so that we can advocate for system change
- So today is all about opening the lines of communication and engagement... we need to keep talking about this issue until we get it right..

Where to from here...



- The Federal Government announced a Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability on 5 April 2019
- The Commission has started conducting hearings and requesting submissions, which will continue over the next few years
- It recently released a paper about health care for people with cognitive disability issues, which is available on its website
- The Commission is requesting submissions at any time but about health issues particularly by 20 March 2020
- This will be one of several submissions I will be making to the Commission, where I will address the systemic issues that we have talked about today
- If you have any particular issues or specific cases of violence, abuse or neglect of which you are aware I encourage you to make a submission
 - It's also vitally important for the Commission to hear about lived experiences from people with disability so if you have any clients that have a story to tell please encourage them to talk to the Commission – there's multiple ways to do that
- There's strength in numbers... so let's lead the way for change!



Thank you.

DISABILITY SUPPORT WORKERS CONFERENCE

MADE POSSIBLE BY:

