Safeguarding the health of NDIS participants

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Overview

- Background
- The Queensland review of deaths in care
- Since the review
- Where to now?

Role of the Public Advocate in QLD

- 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 Queensland review of the deaths of people in care

Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland

https://www.justice.qld.gov.au/public-advocate/systems-advocacy/reports

Background

- People with intellectual or cognitive disability often have multiple and complex health needs and a high mortality rate compared with the general population
- They face significant barriers to accessing appropriate health care and poorer health due to poverty and social exclusion (WHO)
- In most states, apart from the coronial process for reviewing deaths in care, there is no specific process for systemically reviewing the deaths of people with disability

Systemic Review

- The first systemic review of deaths of people with disability in care in Queensland was undertaken by the Public Advocate and published in February 2016
- Objectives of the review:
  - Increase transparency of the current system in reporting and recording deaths in care
  - Assess and analyse the current reporting, recording and investigative processes for this group
  - Highlight key health and risk factors for this group, particularly in relation to deaths that may have been avoidable
  - Identify the systems, practice and process issues associated with deaths in care that were avoidable

Other systemic reviews

Australia

- Only the NSW Ombudsman carries out regular systemic reviews in relation to the deaths in care of people with disability
    - Most recent study released in August 2018

Overseas

- Various investigations and inquiries were undertaken in the **UK** between 2006 and 2013

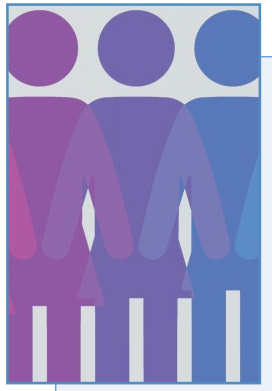
Methodology

- The review focused on the deaths in care of people with disability in Queensland from 2009 to 2014
- 73 cases were examined by an Advisory Panel, consisting of:
  - Heads of agencies with functions relevant to monitoring the provision of supports and services to adults with disability
  - Medical practitioners with specific expertise in the health care of people with disability, in particular people with intellectual impairment.
- Files provided by the State Coroner and various relevant Agencies

73 cases...

All had an intellectual or cognitive disability

- Other disabilities including epilepsy, autism, down syndrome and cerebral palsy



Gender

- 70% male
- 30% female

Ethnicity

- 11% ATSI
- 1 Pacific Islander

Age at death

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

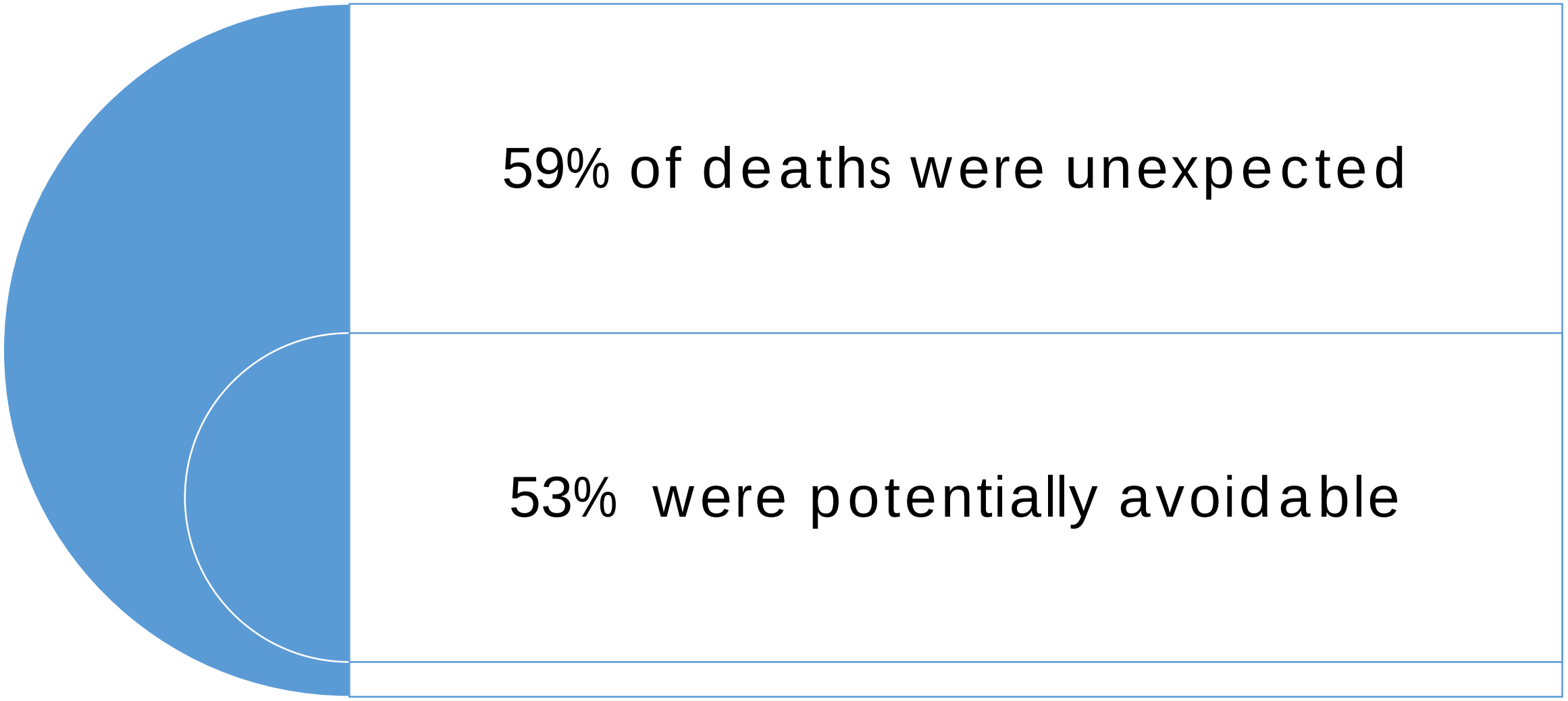
Place of death

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

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



Case studies

A man in his 40's with an intellectual disability lived in a residential disability service. He had been assessed by a speech therapist and a mealtime management plan prepared, setting out the consistency of foods and fluids he could consume safely as well as support for mealtimes. This comprised having soft food cut up into very small pieces and given to him gradually.

On a particular day he was provided with a piece of cake to eat. He started choking, lost consciousness, and later died.

A man in his 20's with intellectual disability, cerebral palsy and epilepsy lived in a disability residential service. He also suffered from gastro-oesophageal reflux and received enteral nutrition.

He was put to bed by his carer and when subsequently checked on in the early morning, was found to have died sometime during the night.

The Coroner found he died from aspiration pneumonia. It had not been diagnosed prior to his death.

Key areas identified for reform

Health practice and standards

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

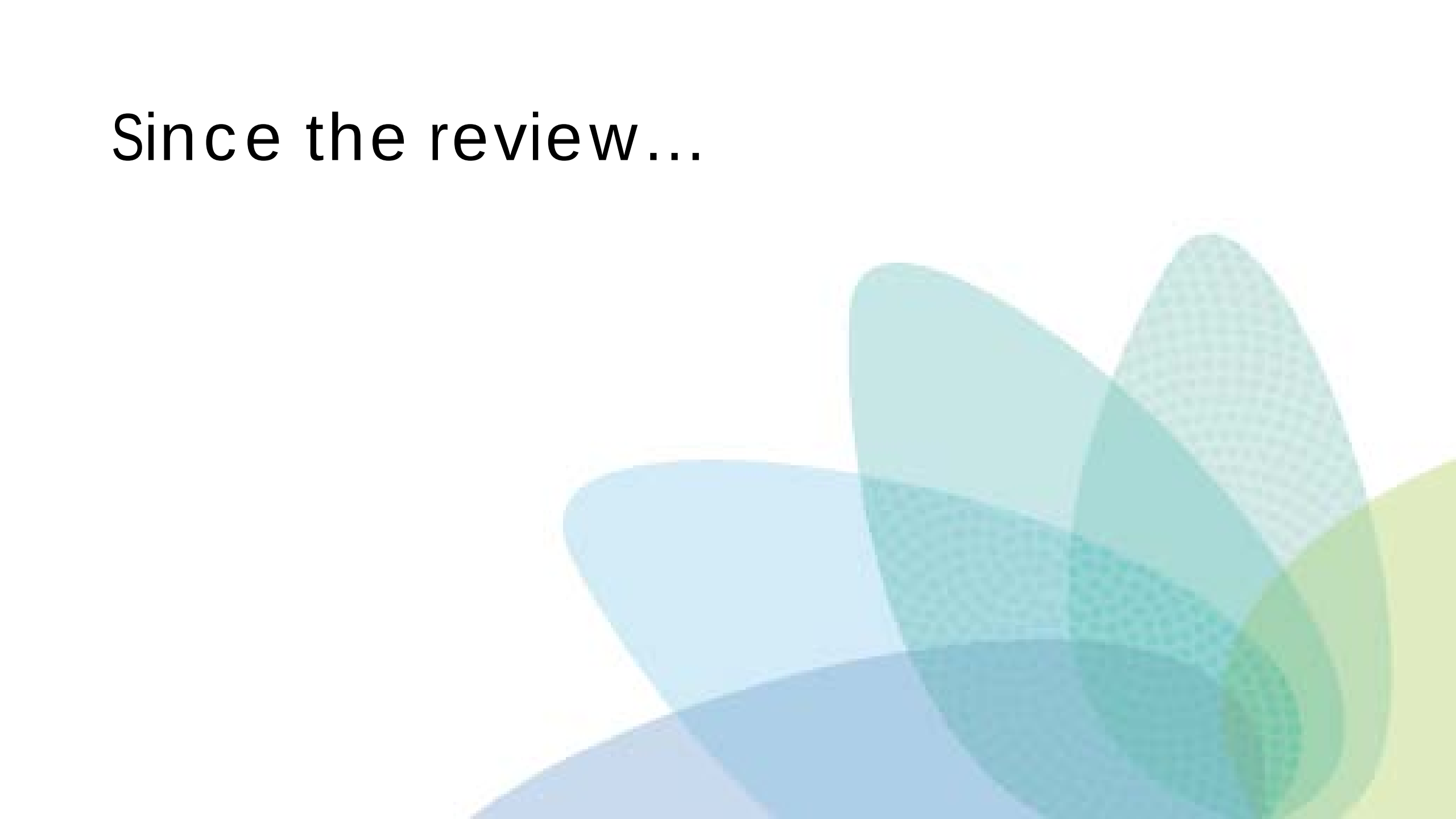
Disability practice standards

- 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

Since the review...



Three years on…

- The Queensland Government has recently finalised an Action Plan to meet the health needs of people in care with disability – includes actions for a wide range of Government Departments to address key issues raised in the review, including a trial project to improve information sharing
- The Office of the Public Advocate is currently considering another review of deaths in care this year
- We need to monitor trends and issues and maintain a focus on the systemic changes required to achieved improved health and quality of life outcomes for Queenslanders with disability

Other reviews

- New South Wales Ombudsman, *Report of Reviewable Deaths in: 2014 and 2015, 2016 and 2017 – Deaths of people with disability in residential care,* August 2018
- Disability Services Commissioner of Victoria, *Review of disability service provision to people who have died 2017-2018*, December 2018
- All of the reports were consistent in the health risks identified for people with disability

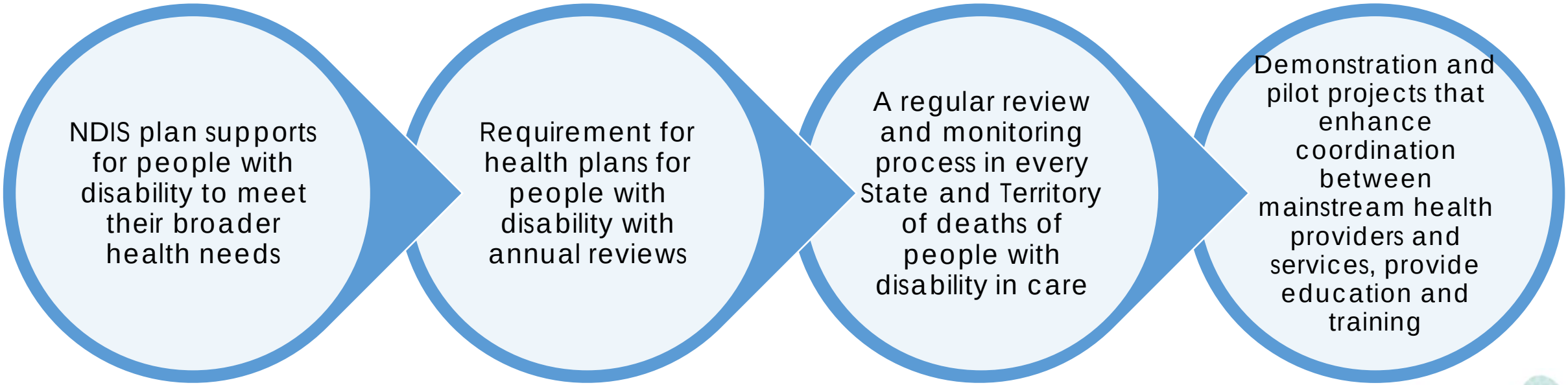
Where to now?

The transition to the NDIS

- The NDIS presents great opportunities but also significant risks as we transition to a model of choice and control that is serviced by an immature market with old providers struggling to adjust to the ‘new world’ of disability service provision and new providers with little experience
- The NDIA has not fully committed to fund the supports required for people with disability to meet their broader health needs

What can we do?

We need to advocate for:



Thank you