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| **Disability Council NSW** |
| Submission to the Legislative Assembly Public Accounts Committee Inquiry into the Management of Health Care Delivery in NSW  |
| **April 2017** |

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# Disability Council NSW

The Disability Council NSW (‘the Council’) was established under the *Community Welfare Act 1987* (NSW), and was re-constituted under the *Disability Inclusion Act 2014* (NSW) on 3 December 2014. The *Disability Inclusion Act 2014* provides a rights-based legislative framework for the Council.

The Council's main responsibilities under the *Disability Inclusion Act 2014* are to:

* Monitor the implementation of Government policy;
* Advise the Minister on emerging issues relating to people with disability, and about the content and implementation of the NSW State Disability Inclusion Plan and Disability Inclusion Action Plans;
* Advise public authorities about the content and implementation of Disability Inclusion Action Plans;
* Promote the inclusion of people with disability in the community and promote community awareness of matters concerning the interests of people with disability and their families;
* Consult with similar councils and bodies, and people with disability; and
* Conduct research about matters relating to people with disability.

The Council has 12 members, including a Chairperson and Deputy Chairperson. Each member is appointed for up to four years by the Governor of NSW on the recommendation of the Minister for Disability Services.

Members are selected to be on Council because:

* They live with a disability
* They are an expert on disability
* They want to improve the lives of people with disability.

The Council’s members have a variety of disabilities and backgrounds. Members include people from Aboriginal or cultural and linguistically diverse backgrounds (CALD), young people, and people from rural and regional NSW. In addition, the Council includes members who are carers or family members of people with disability.

The Council is funded and resourced by the NSW Government through the NSW Department of Family and Community Services (FACS) and is supported by a secretariat team within FACS.

# Executive Summary

There is a fundamental need for management of health care delivery in NSW to recognise in legislation and practice the health care needs of people with disability in ways consistent with Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and other human rights instruments. Accountability for the efficient and effective delivery of health care services is an essential part of providing good health outcomes for every resident of NSW, including people with disability.

The management of health care delivery in NSW should be supported by resources that actually build the capacity of health care practitioners and services to increase skills and services, so that people with disability receive the same standard of care expected by the general population.

The Council expects that the delivery of health care in NSW:

* is consistent with Australia’s obligations under the UNCRPD and other international human rights instruments
* is underpinned by more expansive, comprehensive and human rights centred principles
* is supported by resources that build the capacity and awareness of health care practitioners and services to deliver high-quality services to people with disability, unaffected by conscious or unconscious bias
* is provided on a needs basis, with reasonable adjustments provided to all people with disability who require it
* identifies all persons with disability, and whether they require reasonable adjustments and/or additional health or other services, both so that adjustments can be provided and so health systems can monitor and report on progress
* is clear about the allocation of responsibilities between NSW Health organisations and the National Disability Insurance Scheme (NDIS)
* mandates and actively promotes health care delivery models that are drawn from local and international models of best practice for people with disability
* safeguards people with disability against premature death and health inequalities facing people with disability
* links to mortality data as a measure of health care delivery
* provides both specialised disability health services, and supports greater mainstream capacity, in a similar way as the health system responds to the wide range of other complex and specialised needs, from paediatricians to geriatricians.

# Introduction

The Council welcomes the opportunity to make a submission to the Inquiry, and congratulates the Legislative Assembly Public Accounts Committee for actively consulting with people with disability and their representative organisations in considering the legislative changes and resources required to enable people with disability to experience equitable health care delivery in NSW.

The Inquiry comes at a critical time for the rights of people with disability. With the roll-out of the National Disability Insurance Scheme (NDIS), people with disability, many for the first time, will have choice and control over the services and supports they need to make progress towards their goals. It is more important than ever that frameworks to manage health care delivery in NSW reflect and uphold the human rights of people with disability.

The Council has considered recent developments in law, policy and practice in Australia and internationally as well as results from these consultations to inform this submission.

This **s**ubmission responds to the terms of reference under *e: Any other related matter.*

# Australia’s obligations under the UNCRPD

The NSW Government has two specific health-related obligations under the *Convention on the Rights of Persons with Disabilities*:

Article 25 – Health

1. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes
2. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons
3. Provide these health services as close as possible to people’s own communities, including in rural areas
4. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care
5. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner
6. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.[[1]](#footnote-1)

Article 31- Statistics and data collection

1. Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities
2. Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics
3. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
4. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.[[2]](#footnote-2)

**Recommendation 1:** The Disability Council strongly recommends people with disability are provided with the same range, quality and standard of free and affordable health care as close as possible to their own communities.

**Recommendation 2**: The Disability Council strongly recommends people with disability are provided with programs needed by them, and specifically because of their disability provided without discrimination and uphold the human rights of people with disability.

**Recommendation 3:** the Disability Council recommends statistics and data collection comply with legally established safeguards, to ensure confidentiality and respect for the privacy and comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

**Recommendation 4:** the Disability Council recommends the information collected should be disaggregated and used to help assess the implementation of the States Parties obligations to identify and address the barriers faced by persons with disabilities.

Health inequalities

Many people will have disability at some stage in their lives. For some, the disability will be temporary and for others may be affected for a lifetime.

Negative attitudes, physical barriers and difficulties accessing necessary supports still limit the opportunities of people with disabilities to access good health care, find work, study, socialise and be included in the community[[3]](#footnote-3).

Around 6.8 million Australians (40 per cent) aged 18 years and over report having a disability or long-term health condition. Most (87 per cent) are restricted in carrying out at least one everyday activity such as self-care, mobility or communication.[[4]](#footnote-4)

The Who Health Organisation (WHO) reports that people with disabilities have less access to health care services and experience unmet health care needs. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, depression, Down syndrome) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports[[5]](#footnote-5)).

Disability is extremely diverse, while some health conditions associated with disability result in poor health and extensive health care needs, others do not. However all people with disabilities have the same general health care needs as everyone else and therefore need access to mainstream health care services[[6]](#footnote-6).

People with disabilities report seeking more health care than people without disabilities and have greater unmet need. Health promotion and prevention activities seldom target people with disabilities[[7]](#footnote-7).

Secondary conditions occur in addition to a primary health care condition and are both predictable and preventable. Examples include pressure ulcers, urinary tract infections, osteoporosis and pain[[8]](#footnote-8).

Co-morbid conditions occur in addition primary health conditions associated with disability. For example the prevalence of diabetes in people with schizophrenia is around 15% compared to a rate of 2-3% for the general population[[9]](#footnote-9).

The overall results suggest that people with disability have more health risks or unmet health care needs compared to adults without disabilities[[10]](#footnote-10).Improvements in the availability and access to preventative services and inclusion in public health interventions are needed to potentially reduce the differences in risk of death between adults with disability and without disabilities[[11]](#footnote-11).

Barriers to health care that people with disabilities experience include:

* Affordability of health care services[[12]](#footnote-12)
* Transportation (access to services)[[13]](#footnote-13)
* Lack of appropriate services for people with disabilities[[14]](#footnote-14)
* Physical barriers – access to buildings and medical equipment[[15]](#footnote-15)
* Inadequate skills and knowledge of health workers[[16]](#footnote-16)
* Behavioural health risks (such a physical inactivity or smoking)[[17]](#footnote-17)
* Secondary conditions (such as bladder or kidney infections)
* Not receiving preventive services (such as mammograms)[[18]](#footnote-18)
* Lower quality of care[[19]](#footnote-19)

**Rates of death of people with disability**

People with disabilities are particularly vulnerable to deficiencies in health care services. Depending on the group and setting, persons with disability may experience greater vulnerability to secondary conditions, co-morbid conditions, age-related conditions, engaging in health risk behaviours and higher rates of premature deaths.[[20]](#footnote-20)

Key findings in report Disability and Health[[21]](#footnote-21)show that people with disabilities have an increased risk of premature deaths. They also found that adults with disability were more likely to die of heart disease cancer, cerebrovascular diseases, chronic lower respiratory diseases, unintentional accidents, and suicides and or assaults than those without any disability.[[22]](#footnote-22)

The Council notes with concern the report by the University of New South Wales Chair[[23]](#footnote-23) in Intellectual Disability Mental Health, Professor Julian Trollor et al (February 2017).

Professor Trollor’s research highlights the lack of progress in addressing health inequalities experienced by adults with intellectual disability since the initial publication of mortality data in this group more than a decade ago. The research found adults in this group died on average 27 years earlier than other Australians (54 versus 81 years old) – and that this was not a result of health factors inherent to their disability. This is significantly worse than the much better-known mortality gap between Indigenous and other Australians, which is 69.1 years for Indigenous males compared with 79.7 years for non-Indigenous males, and 73.7 years for Indigenous women compared with 83.1 for non-Indigenous women.[[24]](#footnote-24) This should be cause for great concern within the NSW Government, and particularly within NSW Health.

The report noted that difficulties in health care management arise because clinicians do not have the time, skills, knowledge or attitude to respond to the complex and specialised needs of people with disability, including communication issues. Further, carers of people with intellectual disability report being overstretched by their caring role, and so have difficulty providing health advocacy. Carers also report that some clinicians do not take into account the “views and needs of carers and the views, needs and best interests of the persons for whom they care … in the assessment, planning, delivery and review of services provided to persons who are cared for”, despite this being required under the *Carers (Recognition) Act 2010 (NSW)*[[25]](#footnote-25).

In addition, to this health professionals believe they do not have the skills to deal with behavioural issues of people with cognitive impairments although they wanted to provide them with better care for their patients[[26]](#footnote-26).

According to Professor Trollor’s study – the largest Australian study of its kind – people with intellectual disability were twice as likely to die a potentially avoidable death as the general public.

Understanding the differences in the risk of death in relation to the type of disability is necessary because different groups may need tailored interventions to reduce their risk of premature deaths.

Ways to reduce the risk of premature deaths of people with disability?

* Service delivery: provide a range of modifications and adjustments to facilitate access to health care services
* Improve availability of and access to preventative services and inclusion in behavioural health interventions[[27]](#footnote-27)
* Communicating health information in accessible formats such as Braille
* Empower people with disabilities to maximise their health by providing information, training and peer support[[28]](#footnote-28)
* Health care, promotion and preventative strategies must be tailored to the needs of people with disabilities to effectively modify some factors that increase their risk of premature death (for example, efforts to improve physical activity may require specific assistance in determining safe ways to exercise)[[29]](#footnote-29)
* Promoting community-based rehabilitation to facilitate access for disabled people to existing services[[30]](#footnote-30)
* Apply additional focus on care and case management if they become seriously ill, to aid in timely and appropriate receipt of urgent care[[31]](#footnote-31)
* Identify groups that require alternative service delivery models[[32]](#footnote-32)
* Integrate disability into undergraduate and continuing education for all health-care professionals[[33]](#footnote-33)
* Train community workers so that they can play a role in preventative health care services[[34]](#footnote-34)
* Provide evidence-based guidelines for assessment and treatment[[35]](#footnote-35)
* Promote strategies to ensure that people with disabilities are knowledgeable about their own health conditions and that health care personnel support and protect the rights and dignities of persons with disabilities[[36]](#footnote-36)

**Recommendation 1:** The Disability Council strongly recommends a co-ordinated approach between the NDIA and other Commonwealth agencies; and between the Commonwealth, the State and industry; to address two of the major issues to date of the NDIS:

* the apparent inconsistencies between packages, which appear to be currently dependent on the knowledge and self-advocacy of the participant; the knowledge of the adviser; and where the participant lives, rather than on need

the hearing services which NDIS does not provide, and the lack of Government support for these.blah blah blah

**Recommendation 2:** the Disability Council recommends blah blah blah

# Classification of death

The classification of death is carried out by the medical personnel issuing the death certificate. This procedure is completed using the World Health Organisation (WHO), International Classification of Disease (ICD) coding. When researchers from the UNSW drilled down into their data they uncovered a flaw in the classification system that often listed the underlying cause of death as the intellectually disability itself, rather than the illness or disease that killed them.

The incorrect classification of cause of death comes about from a lack of education about disability. Medical personnel issuing death certificates require education and training on disabilities and health to understand the factors that increase the risk of premature death and disability in itself is not the cause of death but the interplay of health conditions and vulnerabilities that people with certain disabilities experience due to their condition. Disability is extremely diverse, while some health conditions associated with disability result in poor health and extensive health care needs, others do not.

**Recommendation 1:** The Disability Council strongly recommends medical personnel receive education and training to understand disability and health and WHO ICD codes so they can certify the death of a person with disability correctly.

# Mortality data

The Council draws attention to the importance of mortality (retrospective) data which researchers and Government are at risk of losing with the devolution of Ageing, Disability and Home Care (ADHC) and the function of the NSW Ombudsman as they are both functions of the StateCurrently, all service providers, including ADHC-funded and operated accommodation support services and assisted boarding houses, are required, under the *Community Services (Complaints, Reviews and Monitoring) Act 1993*, the *Coroners Act 2009* and *Boarding House Act 2012*, to reportthe death of a person in an accommodation support service at their time of death (or any person temporarily absent at their time of death) to the NSW Ombudsman and Coroner through the Deputy Secretary of ADHC.

The reporting of deaths of people residing in accommodation support services is a safeguarding measure. This information provides significant insights into the prevention of premature deaths of people with disability as well as a means of addressing gaps in policy and practice. The NSW Ombudsman tables a Reviewable Disability Death Report bi-annually to NSW Parliament, making recommendations to NSW Government services such the Ministry of Health, the NSW Police Force, and ADHC.

Under the *3C NSW Ombudsman Act 1974* *- Reportable Incident Scheme,* disability service providers are also required to report to the NSW Ombudsman through the Deputy Secretary ADHC any serious incidents or ‘near misses’. This information provides the NSW Ombudsman and ADHC with valuable information on preventable incidents and allows for continuous improvements and safeguarding.

With the devolution of ADHC, this reporting process will cease. This information allows ADHC to monitor and implement changes in policy and practice to ADHC funded, operated and licenced services. At this stage, it has not been determined how the reporting and monitoring will occur and there is a fear that people with disabilities utilising these services will be at a greater risk.

The introduction of the National Disability Insurance Scheme holds both potential and risk for the safeguarding and support of individuals identified in the Disability Reportable Incidents Scheme and reportable deaths. At the systemic level, mechanisms for clinical governance related to restrictive practices, data collection and reporting around incidence of abuse and death and independent mechanisms for investigation and redress, remain significant unaddressed challenges[[37]](#footnote-37).

The Council strongly recommends the continuation of mortality and incident reporting as a way to safeguard people with disability and to measure the effectiveness and efficiency of health care services in NSW.

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**Recommendation 1:** The Disability Council strongly recommends the continuation of mortality and incident reporting as a way to safeguard people with disability.

**Recommendation 2:** the Disability Council recommends the continuation of mortality and incident reporting as a way to measure the effectiveness and efficiency of health care services in NSW.

# National Disability Insurance Scheme (NDIS)

The Council understands that NSW Health aims is developing pathways to assist in the data collection and reporting of NDIS status for patients accessing NSW Health services for service delivery, billing and monitoring and evaluation purposes, during NDIS transition and into the future.

While this is a step in the right direction, data collection needs to encompass all people with disability, not only those who are NDIS eligible. Data collection around disability is not only required under the UNCRPD, it is also essential to enable the monitoring and reporting of NSW Health’s Disability Inclusion Action Plan, which in turn feeds into the NSW Government’s obligations under the National Disability Strategy.

The collection of disability data is not only the responsibility of NSW Health but also of the primary health care sector.

The Council therefore encourages the NSW Government, particularly NSW Health, to work with both ADHC and the Commonwealth Departments of Health and Human Services to put in place mechanisms for the health data collection of people with disability within all health sectors, as a matter of urgency.

This data should cover:

* People who are eligible and ineligible for NDIS
* People who require and do not require reasonable adjustments
* People who have disability under the definition used by the *Disability Discrimination Act 1992*[[38]](#footnote-38), whether or not they identify as a person with disability.

This data collection should feed into performance reporting frameworks for the monitoring of health care service delivery in NSW to ensure people with disability are captured to drive improvements in the health care delivery system to achieve broader health system objectives for people with disability.

# Privacy

The Disability Council reminds all Government agencies that under the *Privacy and Personal Information Protection Act 1998* and *Health Records and Information Privacy Act 2002*, information about a person’s disability is considered personal health information and must be must be treated accordingly. This must apply to the increased data collected around disability, particularly bearing in mind the risk of re-identification of anonymised data for disabilities with low incidence.

**Recommendation 1:** the Disability Council recommends should capture both people with disability who are eligible and ineligible for NDIS.

**Recommendation 2:** The Disability Council strongly recommends data collection should feed into reporting frameworks for monitoring of health care service delivery in NSW to ensure that people with disability are captured to drive improvements in health care delivery to achieved broader health system objectives for people with disability.

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