



**A 18/71 Victoria Crescent, Abbotsford VIC 3067**

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## **Submission to Disability Royal Commission**

### **Health Issues paper**

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## About Down Syndrome Australia

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission.

Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.<sup>1</sup>

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<sup>1</sup> [http://www.downsyndrome.org.au/down\\_syndrome\\_population\\_statistics.html](http://www.downsyndrome.org.au/down_syndrome_population_statistics.html)

## Submission to Disability Royal Commission Health Issues Paper

Down Syndrome Australia (DSA) welcomes the opportunity to provide a submission to the Royal Commission regarding Health and Intellectual Disability. Our response focuses on issues relating to the experience of people with Down syndrome.

### What do you think about the quality of health care for people with cognitive disability?

People with intellectual disabilities experience significant health inequalities including difficulties accessing the health care they need, barriers to communicating with health professionals, and discrimination within the health system. Down Syndrome Australia has been part of the 'Our Health Counts' campaign led by NSWCID which has been advocating for changes to the health system to address these concerns.

The significant and serious health issues and health inequalities experienced by people with intellectual disability, including Down syndrome, have also been described in the recent Royal Commission hearings.

Research on health and intellectual disability has found that compared to the general population, people with intellectual disability experience<sup>2</sup>:

- over twice the rate of avoidable deaths
- twice the rate of emergency department and hospital admissions
- twice the cost of hospital admissions
- higher rates of physical and mental health conditions
- lower rates of preventative healthcare.
- under-diagnosis of chronic health conditions and lack of active management of risk factors

In addition, the recent report on "Causes and contributors to deaths of people with disability in Australia" undertaken by Professor Julian Trollor for the NDIA found:

- The overwhelming majority of deaths within the scope of the project on "reportable deaths" involved people with intellectual disability.
- The median age at death was substantially (20-36 years) lower than that of the general Australian population.
- There were high levels of co-occurring mental health concerns, including depression, self-harming behaviours and anxiety.

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<sup>2</sup> Trollor & Small (2019). Health Inequality and People with Intellectual Disability: Research Summary. (<https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf>)

- The vast majority of people who died experienced multiple health problems in addition to their disability, including dental problems and epilepsy.
- A considerable proportion of people who died experienced issues that may have negatively affected their eating or drinking, including dental problems and swallowing problems related to Gastro Oesophageal Reflux Disease (GORD), medications and disease processes.
- A high number of in-scope deaths involved people who required communication and/or mobility support.
- There were high rates of polypharmacy, including psychotropic medications being commonly prescribed to people with disability who had died, often in the absence of a diagnosed mental illness.
- The date of the last comprehensive health assessment was unknown for a number of the people who died. In some cases, there was a lack of documented referral and follow-up for people with identified health risks such as diabetes, obesity and hypertension.
- Where reported, it appeared that over half the people who died were outside a healthy weight range. Weight and exercise status were unknown for a significant minority, suggesting that regular monitoring may not have been occurring. There was poor management of lifestyle related risks including insufficient referral and contact with specialists to manage known risks. As well there was a lack of staff awareness of, or compliance with, healthy lifestyle policies.

People with Down syndrome also have some specific health needs particularly in relation to ageing. As the life expectancy of people with Down syndrome has increased, people with Down syndrome are experiencing a higher incidence of age-related health conditions. In addition to longevity, the amyloid precursor protein gene located on chromosome 21 places individuals with DS at a high risk for developing Alzheimer disease. It has been estimated the prevalence of dementia may be as high as 80% in those aged over the age of 65. Often people with Down syndrome have difficulty getting access to appropriate assessment and referrals and may face delays in diagnosis.

Concerns about the quality and access to health care have become front of mind for families in our community with the current COVID-19 crisis. We have conducted a survey of families and have found:

- 48% of families are not confident that the person with Down syndrome will have access to the health care they need during the crisis.
- Significant concerns that other people would be prioritised over the person with Down syndrome if resources were limited
- Concern about whether families would be able to provide support in-hospital during a quarantine situation- and without this support what this would mean for the person with intellectual disability

Some specific quotes from families about their concern about the current situation and the impact on the health services for people with Down syndrome include:

- *My concern is that if Australia gets to an Italy-like situation where hospitals are overflowing and doctors are literally deciding who lives and dies, that the medical world will not see C as a priority, or perhaps even worth saving at all, if it is a choice between her and a 'normal' or healthy person with 'better future prospects'. This is heartbreaking and terrifying. I do not believe her family would ever recover from a situation like that.*
- *Two words- selective treatment. I am concerned that my child with down syndrome's life will not have the same value placed upon it as a person without disabilities. Because the ANZICS states That it is at the discretion of the senior ICU staff to prioritise who gets treatment and That those who have known and long-term comorbidities can be a reason to not prioritise treatment. That she will not receive the same treatment as the next 10 people who walk through the door with COVID-19*
- *Health services are geared to a one size fits all solution. I am concerned a health system under extreme pressure will skim over people living with Down Syndrome, particularly those with severe intellectual delay, and those who as adults can be smaller than average size. I am extremely concerned over what will happen to my son if I fall ill with Covid-19, as there is not alternate informal care.*
- *Every time we seek medical advice he is fobbed of as not having anything serious as he presents differently to Neuro typical people. He always goes downhill a lot quicker than most and requires to be hospitalised . He has an extremely high pain threshold and very weak immune system*

Many families are also concerned that the focus on tele-health during this crisis is creating difficulty for their families. The view is that communication can become even more difficult for people with intellectual disability over video conferencing and therefore it can be difficult to access needed services. People are also concerned about what the situation will mean in terms of access to physio or other allied health services for small children who may not be able to engage over telehealth.

### **Question 2:**

#### **B. Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?**

One of the significant barriers experienced by people with Down syndrome and their families relate to health professionals understanding of Down syndrome. A 2017 survey of people with Down syndrome and their families found that:

- nearly a third of respondents had concerns about the safety and wellbeing of the person with Down syndrome within the health system.
- 77% of respondents indicated that health professionals would benefit from workshops or webinars on Down syndrome.



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- 70% of families indicated that the biggest barrier that they experience within the health system is lack of up-to-date understanding about Down syndrome. Many included examples of doctors not including the person with Down syndrome in discussions or making incorrect presumptions about their capabilities.

These findings are perhaps not surprising given that general practitioners and nurses have minimal training in intellectual disability health care. An average of 2.6 hours of an entire medical degree is dedicated to intellectual disability while most nursing degrees have no content specific to intellectual disability. The content which is provided is often focused on specific health related issues rather than communications.

Other key barriers that have been described during the Royal Commission health hearings:

- Health professionals wrongly assuming symptoms relate to a person's disability
- Health professionals wrongly assuming people with disability don't deserve the same level of health care as people without a disability.
- A lack of proactive support for preventative health care measures, including recommended vaccinations, dental check-ups, comprehensive health examinations and allied health referrals. This lack of proactive support is manifested in both a low uptake of preventive health measures by people with intellectual disability, as well as a lack of proactive direction provided by health care professionals.
- A limited use of communication plans and other communication accommodations which can limit a person with intellectual disability from adequately communicating their health concerns to staff.

### Question 3:

#### **B. Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?**

People with Down syndrome report that they have difficulty managing the interface between the NDIS and the State health systems. There has been significant work in recent months by the NDIA to address these issues and provide greater flexibility around usage of NDIS funds to support health costs. The introduction in October 2019 of the ability to utilise NDIS funds to pay for additional disability-related health costs has alleviated some of the difficulties. There continues to be issues around communication and understanding about the interface between the health systems and NDIS.

**Question 4:**

**A. What do you think should be done to fix the problems people with cognitive disability have in getting health care?**

There has been significant work undertaken on the steps required to improve health care for people with intellectual disability. In August 2019, the Government convened a roundtable of experts across a range of disciplines to discuss the challenges facing people with intellectual disability in accessing appropriate health care, and the opportunities to improve the system. A range of key recommendations came out of this roundtable including:

- Improvements to education of health professionals on intellectual disability
- Implementing the Primary Care Enhancement Program through the Primary Health Networks
- Developing a National Roadmap for improving quality of health services
- Establishing a network of centres of excellence on the health of people with intellectual disability, with at least one in each jurisdiction, building on existing centres.
- Promoting better uptake of the existing MBS health assessment items for people with intellectual disability.
- Paying priority attention to the issues of transition from paediatric to adult care for people with intellectual disability, with better models of care and coordination to be developed for all life stages.
- Developing a national data asset on the health of people with intellectual disability.
- Considering the needs of people with intellectual disability and their families in the development of all health policies and initiatives.

We are pleased that the Department of Health is planning to reconvene this group of experts to continue

Additional issues which should be considered include:

- Building the capacity and skills of health professionals to understand and work with people with an intellectual disability to improve health outcomes. This must include additional
- Increasing the number of specialists in intellectual disability medicine – set quotas for the number of medical specialists in intellectual disability.
- Providing better access to screening and diagnosis of dementia for people with Down syndrome.
- Provide health care facilitators to people with complex health needs.
- Recognise the role of people with intellectual disability as educators of health professionals.

### **Question 5:**

#### **Why do people with cognitive disability experience violence, abuse, neglect or exploitation in health care? What are the causes?**

As previously described, health professionals have limited training and understanding about intellectual disability. As a result, they often struggle to communicate and provide appropriate care and services. There is limited use of communication plans or other communication accommodations which can limit a person with intellectual disability from adequately communicating their health concerns to staff. It should be noted that Down Syndrome Australia has been funded through an NDIS ILC grant for a project which is focused on addressing communication barriers between health professionals and people with Down syndrome.

In addition to communication issues, there are also significant concerns about discrimination which can occur within the health sector. Some health professionals do not have a contemporary understanding of disability and defer to parents or carers rather than focusing on the right of the person with intellectual disability to be at the centre of all decisions relating to their health. In addition, health professionals make assumptions about the care which should be provided to a person with intellectual disability.

There can also be resourcing issues which can make it difficult for health professionals to provide adequate care and support. With limited time provided for GP consults, or limited staff within the hospital environment, often people with intellectual disability are not provided with adequate levels of support or time to communicate their needs.

### **Question 10:**

#### **Have we missed anything? What else should we know?**

Another key health issue which should be considered by the Royal Commission is around the information and support provided to parents who receive a prenatal diagnosis of Down syndrome. The misinformation, lack of support, and pressure to terminate pregnancies constitutes another form of violence, abuse and neglect within the health system for people with disabilities and their families.

The majority of pregnant women in Australia undertake the combined first-trimester screening which includes screening for chromosomal conditions such as Down Syndrome. A smaller number opt to undertake the Non-Invasive Prenatal Screening (NIPS) which is available at 10 weeks of pregnancy. The Department of Health provides guidelines which indicate that doctors should support women to make 'informed decisions'.

There is considerable evidence, despite appropriate guidelines, that appropriate information about screening is often not provided to women and acceptance of screening is frequently presumed.

Once a result is provided, if an unexpected result is received, families are often pressured to make a decision to terminate even when this goes against their personal beliefs.

Data from Western Australia suggests that in Australia, most women for whom a confirmed prenatal diagnosis of fetal Down syndrome is made, choose to terminate the pregnancy (93%). There is significant concern that these termination rates are impacted by the lack of balanced information provided to families during prenatal screening. The lack of support from some medical professionals about continuing a pregnancy after a prenatal diagnosis also may influence parents' decisions.

In 2017 Down Syndrome Australia conducted a survey and found that in our sample, more than a third of women who had a pregnancy with a prenatal diagnosis of Down syndrome felt pressure from medical professionals to terminate the pregnancy. For example, one respondent stated:

“We were very pressured to have a termination. They said our little boy was going to pass away due to his health issues, that he would end us going through so many surgeries and he would suffer, we were better off terminating before to save him the suffering. In the end we have a happy little boy because we refused to listen to this advice. I hate to think of all the parents who did listen to their doctors and missed the chance to meet their child”

These findings are consistent with the results of a survey published by Down Syndrome Tasmania of Australian women who have a child with Down syndrome and received a high chance result during pregnancy. Amongst these women 62% indicated that negative language was used by health professionals when informing the women of the high probability result. One woman described her experience as 'They weren't just negative, they told us our baby would most probably die in utero but if she survived she would be in hospital for most of her "short" life, never walk, talk or have any quality of life'.<sup>3</sup>

Some anecdotal reports have indicated that women are being told that a child with Down syndrome can never go to a mainstream school and that parents will have to give up their careers to support the child. A post to the parenting blog Mamamia.com.au told of a woman who decided to terminate her pregnancy to avoid pain for her child : “We ended little Dot’s life because we didn’t want her to endure a lifetime of pain. We knew that she would need constant medical attention, and we felt we couldn’t stand by and watch her as she struggled physically and intellectually throughout her (possibly short) life, when we couldn’t do anything to help her.” This description of life with Down syndrome is at odds with research findings and the experience of most families.

There are also concerns that in some cases families are seeking terminations without the appropriate follow up tests after a positive result on NIPS. The marketing of NIPS uses terminology such as “unsurpassed accuracy” and “Simple, fast, reliable” , and statements such as

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<sup>3</sup> Kelly, R. (2016). Carrying a baby with Down syndrome: Women’s experiences of prenatal screening, diagnosis and pregnancy care. (published by Down Syndrome Tasmania).



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“non-invasive prenatal test offering 99% accuracy” which can result in families having an view that NIPS provides a definitive result and that there is no need for additional testing.

The misinformation, coercion and lack of support provided to parents undergoing prenatal screening constitutes a form of neglect and abuse within the health care system. These experiences have significant impacts on both the decisions made by families, but also have long-term consequences for the wellbeing of family members. Many parents of children with Down syndrome remark that the way the diagnosis is presented can be traumatic.