Submission to Disability Royal Commission

Emergency Planning and Response

July 2020

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.[1]

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[1] Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from **https://www.downsyndrome.org.au/about-down-syndrome/statistics/**

Submission to Disability Royal Commission Emergency Planning and Response Issues Paper

Down Syndrome Australia (DSA) welcomes the opportunity to provide a submission to the Royal Commission regarding Emergency Planning and Response. Our response focuses on issues relating to the experience of people with Down syndrome and their families.

Question 1: What needs to be done by governments to increase the safety and wellbeing of people with disability during an emergency such as the COVID-19 pandemic or the Black Summer bushfires?

Question 3: What is the experience of people with disability in getting assistance and information in an emergency? How does the lack of assistance and information expose people with disability to violence, abuse, neglect and exploitation?

The recent bushfires and COVID-19 pandemic have highlighted the need for a comprehensive approach to providing the right support to people with a disability as part of Emergency Planning and Response. These events have had a significant impact on people with intellectual disabilities including those with Down syndrome and highlight the need for work to be done to ensure that future emergency responses take into account the needs of people with disabilities.

Emergency preparedness and risk reduction are essential in minimising fatalities in times of crisis, and in securing the right to life with dignity.[2] Research highlights that people with disabilities are twice as likely to die or be injured in natural disasters than the general population[3]. The social isolation experienced by people with disabilities creates additional barriers to accessing assistance and support during emergencies. The risk to people with disabilities is often compounded due to the fragmented nature of services and systems where responsibilities for supporting people with disabilities in disasters is uncertain[4].

Article 11 of the CRPD on "Situations of risk and humanitarian emergencies" states that "States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

The recent emergencies experienced in Australia has highlighted the significant issues people with intellectual disabilities have in accessing appropriate information, services and supports in times of crisis. Down Syndrome Australia (DSA) has been working closely with its members throughout this period to ensure people with Down syndrome and their families are appropriately supported.

[2] World Health Organization (2007). Risk reduction and emergency preparedness: World Health Organization six-year strategy for the health sector and community capacity development. World Health Organization (WHO).

[3] University of Sydney (2017). Disability inclusive disaster preparedness in NSW. Retrieved from **http://sydney.edu.au/health-sciences/cdrp/projects/disasterdisab**

[4] University of Sydney (2017).

Information

One of the critical issues experienced by our members has been difficulty in accessing information. A survey conducted by DSA found that families were looking for tailored information about the impact of the pandemic on people with Down syndrome. They were turning to the Down syndrome organisations as a trusted source of information. Families were concerned about a lack of information in plain language/Easy

Read formats and a lack of information relating specifically to Down syndrome. Survey respondents indicated that the most common information they required included:

- Information about changes to the NDIS, and how to use their NDIS funding under the current situation, especially concerning telehealth and the interface with education,
- Information regarding Government benefits,
- Health and Mental health,
- How to stay fit/active during isolation,
- Available support to help people with Down syndrome understand social distancing, and
- Support with education and distance learning.

The 'An Open Letter to the National Cabinet'[5] which was sent by a coalition of Disability organisations also highlighted this issue, reporting that 67% of people with a disability in Australia found government information and communication regarding COVID-19 inaccessible and difficult to understand.

DSA recommends that governments ensure that all emergency information and announcements be fully accessible to people with disabilities, including the production of information in plain language/Easy Read formats and the use of captioning and AUSLAN interpreters in all government announcements to assist people with an intellectual disability.

Health

People with intellectual disabilities have worse health outcomes than the general population and frequently experience significant barriers when accessing health care. These barriers are well documented and include issues communicating with health professionals, discrimination within the health system, and lower rates of preventative health care.[6] The Department of Health is currently working on addressing some of the issues concerning health care for people with an intellectual disability with a recent roundtable and several new initiatives underway.

Barriers to health care for people with disabilities are often exacerbated in times of crisis due to limited resources and additional pressures on an already strained health care system. The systemic discrimination against people with an intellectual disability can raise concerns about whether or not people will be

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[5] Children and Young People with Disability Australia (2020). An Open Letter to the National Cabinet: Immediate actions required for Australians with disability in response to Coronavirus (COVID-19). Retrieved from **https://mcusercontent.com/c75d12b0ea3d513c036636c7d/files/dcfff274-d57b-4f60-89de-6382b7fbb293/An_Open_Letter_to_The_National_Cabinet_Final_small.pdf**

[6] Trollor, J & Small, J (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**)

disadvantaged when it comes to access to limited health resources. This contravenes the Convention on the Rights of People with Disabilities (CRPD) which states that people with a disability have a right to '*the highest attainable standard of health and access to health and rehabilitation services*'.[7]

Families in our community expressed their concerns about the quality and access to health care with the current COVID-19 crisis. Our survey of DSA members found that a key concern was that people with an intellectual disability would be disadvantaged if there is rationing of health resources.

In particular:

- 48% of families were not confident that the person with Down syndrome would have access to the health care they need during the crisis,
- There were significant concerns that other people would be prioritised over the person with Down syndrome if resources were limited, and
- Families were concerned whether they 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.

There was a particular concern around access to intensive care under a scenario where there was a potential for rationing of heath care services. It is important that the Government makes it clear that during a health crisis there will be no discrimination against people with disabilities in accessing the care they require, including intensive care or access to ventilators.

The establishment of the Advisory Committee for the COVID-19 Response for People with Disability and the development of the Management and Operational Plan for People with Disability was an essential step in managing and preventing the transmission of COVID-19, and ensuring that people with disability have equal access to health care. The Operational Plan clearly stated that people with a disability have the same rights to health care as other people in the community. This Plan was released in late April and provided reassurance to the community about access to health care.

Importantly the Advisory Committee included people with lived experience, key advocates, as well as professionals and researchers. Ensuring that the Committee included people with lived experience improved the credibility and effectiveness of the Committee.

DSA believes there is a need to develop structures so that advisory committees and operational plans can be formed or re-established quickly to respond to an emerging health crisis or Natural disaster. Future operational plans need greater transparency regarding roles and responsibilities at a federal, state and territory level as well as greater coordination and communication between federal and state governments and the health and disability sectors to facilitate effective implementation and prevent gaps in essential support. This should involve working with peak bodies who can provide input and assistance in how these plans should be operationalised at a state and territory level.

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[7] Australian Human Rights Commission (2020). Human Rights and People with Disability. Retrieved from **https://humanrights.gov.au/sites/default/files/content/letstalkaboutrights/downloads/HRA_disability.pdf**

Mental Health and Support

Mental and emotional health is a fundamental part of life and significantly impacts an individual's thoughts, behaviours and emotions. People with intellectual disability are at an increased risk of feelings of loneliness, social isolation, and negative self-perceptions due to the misconceptions and stigma that often surround disability.[8,9] The higher rates of social isolation and loneliness place people with disability at higher risk of developing mental health issues, including depression and anxiety.[10]

Before COVID-19, nearly 45% of people with intellectual disability reported feeling lonely.[11] For many, these feelings have been intensified due to the increased pressures of living in quarantine. This comes at a time when social activities, drop-in centres, and family respite services are either unavailable or closed, causing further isolation and disruptions to daily routine. Although lockdown restrictions are easing, people with disability may be forced to self-isolate for more extended periods due to poorer health and being at increased risk of infection. It is essential to ensure that people with intellectual disability have appropriate mental health supports in place in crisis. Federal and state governments should, as a priority, expand access to mental health plans.

There is also a need for the provision of targeted online counselling services for people with disabilities to help manage the emotional and mental health pressures that can arise during a crisis.[12] Funding for peak organisations should also be provided to assist in establishing online social supports for people with intellectual disability and their families. This is especially important as people with disability are likely to experience increased social isolation during pandemics compared to those without a disability.

Education

Children with disabilities face significant barriers in accessing education and are among the most-at-risk for educational neglect and exclusion, particularly in emergencies.[13] The outbreak of COVID-19 has revealed serious issues for students with intellectual disabilities in terms of accessing education. Many families in our community reported experiencing a lack of support due to shifting to home-schooling and online learning. Families also expressed their frustration at being unable to utilise NDIA support workers to assist with educational needs. The results of our recent DSA member survey further highlighted their challenges regarding education:

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[8] FaHCSIA. (2009). Shut Out: The Experience of People with Disabilities and their Families in Australia (pp. 1-79). Canberra: Australian Government.

[9] Gilmore L, Campbell J, & Cuskelly M (2003). Developmental Expectations, Personality Stereotypes, and Attitudes Towards Inclusive Education: community and teacher views of Down syndrome. International Journal of Disability, Development and Education, 50(1), 65-76.

[10] Mental Health Commission NSW (2017). Intellectual Disability. Retrieved from **https://nswmentalhealthcommission.com.au/mental-health-and/intellectual-disability**

[11] Alexandra P, Angela H, Ali A (2018). Loneliness in people with intellectual and developmental disorders across the lifespan: A systematic review of prevalence and interventions. *J Appl Res Intellect Disabil*.;31(5):643-658. doi:10.1111/jar.12432

[12] People with Disability Australia (2020). Immediate Proactive Response to Coronavirus (COVID-19) for Australians with Disability. Retrieved from **https://pwd.org.au/covid-19-plan/**

[13] Australian Coalition for Inclusive Education (2020). Providing inclusive education for children and young people with disability in a 'time of crisis'. Retrieved from **https://acie105204494.files.wordpress.com/2020/04/acie-providing-inclusive-education-in-a-time-of-crisis-apr20-1.pdf**

- 22% of parents of school-aged children with Down syndrome were not confident that they would be able to provide the level of support their child required to learn, and

- Many respondents expressed a desire for educational support, including connection to support services, being able to access activities to support education, and having access to activities they can print off to facilitate home learning.

The Australian Coalition for Inclusive Education (ACIE) has developed the 'Providing inclusive education in a time of crisis: principles and recommendation' outlining several important recommendations to ensure that children with disability receive inclusive education during the COVID-19 pandemic. This includes:

- Support and delivery of education for students with a disability must be further considered in future emergency response plans,
- The government should look at developing an NDIS-specific response to emergencies which includes increasing flexibility for people with disabilities and their families to utilise their plans to support education, and the provision of additional funding if required during a crisis, and
- The development of an online education strategy for children with intellectual disabilities to assist in participation in mainstream education and ensuring education resources are available in Easy Read format is also critical. It is essential that students with a disability stay connected to their peers and teacher and are not diverted into a segregated online learning environment.

DSA endorses the recommendations and strategies outlined in the ACIE paper to ensure that children with an intellectual disability receive appropriate educational support in times of crisis. To access the ACIE document, please click **here**.

Role of Peak Disability Organisations

Peak organisations play an essential role during an Emergency Response. They take on additional work to develop and disseminate appropriate information and support to people with disabilities.

For example, in response to the COVID-19 pandemic, the DSA Federation developed a range of resources to inform and support the Down syndrome community. This included resources regarding learning from home, the NDIS, physical and mental health, and COVID-19 and Down syndrome. These resources were well received with statistics showing more than 400 downloads of our Easy Read COVID-19 resource and over 3,000 views of our COVID-19 resource page during a 3-month period.

In response to our recent survey, DSA members indicated that the types of resources/services they were seeking from their Down Syndrome Federation during the pandemic included:

- Communication/information on COVID-19 outside of social media. This included wanting personalised information through targeted emails or individual phone calls
- Educational support including connection to services, activities to support education, and activities to print off,
- Social stories from people with Down syndrome and their families,

- Advocacy on the government's COVID-19 supplement which was not available for the Carers Allowance or the Disability Support Pension,
- Understanding changes to NDIS and how to get support

- Ideas for home therapy,
- Online forums/social opportunities for people with Down syndrome and separately for family members, and
- Ideas for activities for adults with Down syndrome such as opportunities for connecting online with others.

Peak bodies are a source of invaluable information and support to people with disabilities and act as a channel between governments and our members. Additional funding should be made available to peak organisations in times of crisis to cover the costs associated with the development and provision of additional information and supports during these periods.

Question 2: What supports are required to ensure people with a disability are not at risk of violence, abuse, neglect and exploitation during an emergency? For example:
- Health support
- Financial support

Financial Support

People with disabilities are far more likely to experience higher rates of poverty and unemployment, then the general population.[14] They are at particular risk during any economic or health crisis. For example, the COVID-19 Pandemic has had a significant economic impact with growing rates of unemployment being experienced across the country. It is integral that people with disabilities are included in the government's long-term response to unemployment post-crisis to ensure they are not further disadvantaged.

From 27 April 2020, a Coronavirus supplement of $550 per fortnight was available to people receiving a JobSeeker or other support payment for six months. This supplement, however, is not available to recipients of the Disability Support Pension (DSP) placing people with disabilities at even higher risk of poverty[15]. This comes at a time when many people with disabilities are experiencing rising costs associated with healthcare, groceries and hygiene/sanitising equipment.[16] In future national crises such as the COVID pandemic, the Government needs to ensure that people with disability have access to additional financial supports. This should include including the DSP in any supplement payment and also exploring the possibility of extending any financial support available for people with disabilities due to acknowledge the increased difficulty people with disabilities are likely to experience regaining employment post-COVID-19.

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[14] Pricewaterhouse Cooper (2011). Disability expectations: Investing in a better life, a stronger Australia. Retrieved from **https://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf**

[15] Children and Young People with Disability Australia (2020).

[16] People with Disability Australia (2020). People with Disability and COVID-19. Retrieved from **https://pwd.org.au/experiences-of-people-with-disability-during-covid-19-survey-results/**

Access to PPE

People with disabilities may be at increased risk during a health crisis, as is the case with COVID-19 due to pre-existing health conditions and/or reliance on others to provide supports. One of the significant concerns raised by people with disabilities and support workers has been limited access to necessary

supplies including hygiene/sanitising products, personal protective equipment (PPE), medications, cleaning products and groceries throughout the pandemic.[17,18] In a 2020 survey conducted with 2,341 support workers, many respondents felt that the disability sector was dangerously overlooked in the national COVID-19 response placing people with disabilities and support workers at unnecessary risk of contracting the virus.[19]

People with disabilities should have access to disability-specific packages similar to those provided to older people which includes access to PPE, sanitiser and other health-based initiatives. Additionally, guidelines regarding the triage of medical treatment should be reviewed to ensure that people with disabilities have equitable access to health care and supplies.

Question 5: How can people with disability be included in emergency planning and responses to ensure strategies that reduce risk of violence, abuse, neglect and exploitation?

There has been growing recognition of the importance of including people with intellectual disabilities in the development and delivery of information, services and supports. The Sendai Framework for Disaster Risk Reduction (2015-203) was adopted on 18 March 2015 at the Third United Nationals World Conference on Disaster Risk Reduction. The framework sets out specific priorities for action to ensure the effective management of disasters. One of the guiding principles of the Sendai Framework states:

> *"Disaster risk reduction requires an all-of-society engagement and partnership. It also requires empowerment and inclusive, accessible and non-discriminatory participation, paying special attention to people disproportionately affected by disasters… A gender, age, disability and cultural perspective should be integrated in all policies and practices…."*

The establishment of the Advisory Committee for the COVID-19 Response for People with Disability and the development of the Management and Operational Plan for People with Disability has been a positive step in ensuring that people with lived experience of disability are involved in emergency preparedness and management.

The Advisory Committee has met regularly throughout this period, and open communication between the disability and health sector as well as government agencies and response groups has assisted in ensuring that relevant information is disseminated promptly and that plans reflect the needs of people with disability. These efforts have been positive, and it is essential for the government to further develop and expand on

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[17] People with Disability Australia (2020).

[18] Children and Young People with Disability Australia (2020).

[19] University of New South Wales (2020). The disability workforce and COVID-19: initial experiences of the outbreak. Retrieved from **http://unsworks.unsw.edu.au/fapi/datastream/unsworks:66998/bincdf1e78b-f5e3-470d-8601-ee2cdadb3d42?view=true&xy=01**

these responses to address the needs of people with disability in future crisis. In addition, more funding should be provided to peak bodies to facilitate the involvement of people with intellectual disabilities in matters that directly impact them.

In addition to disability specific advisory groups, it is also essential that the consideration of people with disabilities is embedded within all mainstream initiatives and responses, rather than just being treated as an "add-on" consideration. For example there were a number of committees developed as part of the Covid response which did not include representation from people with disabilities and therefore disability was being left out of mainstream responses.

Question 6: How are people with disability in closed facilities and segregated settings placed at increased risk of violence, abuse, neglect and exploitation during emergencies? What is needed to ensure people with disability in these settings are safe if facilities are locked down or evacuated?

Question 7: How can people with disability be protected from violence, abuse, neglect and exploitation when oversight and safeguarding practices are affected during emergencies? Should additional practices be in place during emergencies? If so, what should those be?

People with disability in segregated settings are at increased risk of violence, abuse and neglect generally. As noted by the Senate Inquiry in 2015[20]:

> "It is well-known that 'where people with disabilities live and the cultures of the organisations that provide services, in particular residential services, are significant factors that impact on the risk of violence, abuse and neglect'. Deakin University noted that it is the 'isolation from broader society and the "closed" nature of disability services' that can lead to a 'corruption of care'."

This isolation can be increased by an emergency situation, and therefore the risks of violence, abuse and neglect are heightened.

This was seen during the COVID-19 pandemic with a range of concerns being raised about people with disabilities who were living in segregated environments or group homes.[21] There were reports of an increase in restrictive practices in group home settings with people with disabilities being locked in their rooms in an attempt to curb the spread of COVID-19.

It is essential that any Emergency Plans should include consideration about how to mitigate the increased risks for people with disabilities within these segregated environments including through providing information and education to staff about appropriate management as well as oversight measures and outreach services to ensure that the human rights of people with disability are upheld.

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[20] Parliament of Australia (2015). Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability. Retrieved from
https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect
[21] Children and Young People with Disability Australia (2020).

The operation of Australian Disability Enterprises (ADEs) throughout the pandemic has also raised concerns. At the same time that most other businesses were ceasing face to face interactions, many ADE's continued on a 'business-as-usual' basis throughout the pandemic placing people with intellectual disabilities at increased risk of exposure to COVID-19. The federal government should urgently review the need for temporary closures of ADEs during emergencies, and the provision of additional ongoing support to assist people with intellectual disability follow health guidelines regarding social distancing, hand washing and other hygiene practices to stop the spread of COVID-19 in ADEs.[22]. In addition, it is essential that funding

provided for the ADE services through NDIS can be used flexibly during this period to ensure people can get the support they need at home.

Summary

Emergency planning and responses are vital in minimising injury and fatality in times of emergency and in securing the right to life with dignity for people with disability. The recent emergencies in Australia have underscored several key areas that require urgent attention to ensure the human rights of people with disability are upheld during times of crisis. These include:

- Development of relevant up-to-date disability specific information in an accessible format.
- Establishment of Advisory Committees which include people with disabilities that can provide advice to Government about the emergency response in relation to disability
- Actions to address social isolation and specific services to support mental health for people with disabilities.
- Comprehensive approach to ensure students with a disability are not disadvantaged during a crisis.
- Appropriate funding of peak organisations who play an essential role in the provision of information and support during emergencies.

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[22] Disability Advocacy Network Australia (2020). Government-funded workplaces putting up to 20,000 Aussies with intellectual disability in the firing line of COVID-19. Retrieved from **https://www.dana.org.au/covid-19-ades/**