

Submission: Draft National Disability Advocacy Framework

Ensuring a strong voice for all people with Down
syndrome, their families and carers

8 July 2022



Down Syndrome
New South Wales



About Down Syndrome NSW

The Down Syndrome Association of NSW was established in 1980 by parents of young people with Down syndrome. As the children of the founding members grew to adolescence and adulthood, so too our services extended to all life stages. We now provide information and support, advocacy, capacity building workshops, training in schools, community participation programs, pre-natal expert advice, new parent resources and support and specialist employment preparation and connection.

We are an enthusiastic team of professionals with expertise in our relevant fields of service provision, support and advocacy. Some of us have lived experience with a family member with Down syndrome, some bring a range of expertise and industry experience. We are here to support you – all working together to help our members with Down syndrome achieve their full potential.

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Introduction

Down Syndrome NSW is pleased to provide input into the draft National Disability Advocacy Framework (NDAF), developed by the Department of Social Services (DSS) to underpin the shared commitment between the Commonwealth, state and territory governments to develop a nationally consistent framework for all types of advocacy – disability, systemic, individual, self. Following on from the 2012 National Disability Advocacy Framework, this draft presents an opportunity to better align the principles, outcomes and overarching objective with current day needs of people with disability, their families and carers. Central to this is the role advocacy organisations like Down Syndrome NSW play in ensuring the voices of all people with disability are heard, in line with the intent of the NDAF.

In a world that is becoming increasingly homogenised, Down Syndrome NSW plays a key role in supporting, informing and advocating for people with Down syndrome, their families and carers. Our community shares unique experiences, synergies and a strong sense of connection. From our over 40 years in the advocacy space, it continues to be clear to us (if not increasingly clear in recent years) of the need for diagnosis/disability-specific expertise and advocacy. To strengthen this further, in attending the consultations it was clear that people with disabilities other than Down syndrome, their families and carers have often found it difficult to secure advocacy that understands and is tailored to their needs as they do not have access to disability-specific advocacy organisations.

Down Syndrome NSW supported the draft NDAF and looks forward to seeing the supporting workplan that will bring the framework to life, coupled with robust transparent reporting and accountability. In this, we would hope the principles enshrined in the social model of disability are adopted to ensure that there is a responsibility on government, agencies, organisations and communities to actively include and support people with disability and enact change, rather than simply expecting people with disability to fight to have a voice with little or no impact. We advocate for a holistic approach to the full ecosystem of change.

In canvassing the views our members, attending consultations in NSW and drawing on our expertise, we offer the following feedback in relation to the NDAF to ensure it best enshrines what high quality, representative and equitable advocacy aspirations for all Australians with disability.

Feedback: Draft National Disability Advocacy Framework

Down Syndrome NSW commends the work of DSS in developing the draft NDAF provides the following feedback. An overall observation of the NDAF is the role of disability advocacy organisations and of families and carers is not well articulated or acknowledged. We know from our members that whilst self and individual advocacy are exceptional when working well, many people with Down syndrome require additional support to access information, meaningfully contribute, enhance their capacity and have their voices heard.

Principles

Down Syndrome NSW supports the alignment of the NDAF with existing important legislative frameworks, which ensures consistency and synergy from the outset, namely:

- United Nations Convention on the Rights of Persons with Disabilities
- Disability Discrimination Act 1992
- Australia's Disability Strategy 2021-2031
- Closing the Gap National Agreement
- NDIS Quality and Safeguarding Framework
- Information Linkages and Capacity Building Program

We support these as critical complementary frameworks that have a necessary influence on the NDAF.

We support the principles as laid out, noting that a presumption of capacity to make decisions is paramount though at times requires support to enable and enhance that capacity for some individuals with Down syndrome. It is pleasing to see disability advocacy highlighted in the principles as an essential tool for fostering the full and effective participation and inclusion of people with disability in society. Our members would like to see acknowledgement of the role of parents, siblings and carers as key advocates for both children and adults with disability as part of the principles. We know parents, siblings and carers provide critical advocacy, inclusion and participation support, investing much time, effort, finances and upskilling themselves to do so.

Outcomes

Down Syndrome NSW supports the intended outcomes, as articulated in the NDAF. We acknowledge the desire of the NDAF to achieve and uphold the broad outcomes themes of:

- equality of rights and freedoms,
- improved choice, voice and control,
- participation in all aspects of civil, economic, political, cultural and social life,
- supported interactions and access,
- tailored support for Aboriginal and Torres Strait Islander peoples with disability,
- culturally appropriate support for culturally and linguistically diverse communities,
- robust, clear and accessible complaints and feedback mechanisms,
- demographic representation in individual advocacy to reflect need,
- involvement in the planning, delivery and evaluation of government policies, programs and services in disability and beyond,
- increasing community awareness of barriers to people with disability, stigma and valuing advocacy supports.

In these outcomes, we would seek for there to be the addition of some sort of outcome in terms of measurable change and impact from advocacy at all levels, that is clear and reported. It may also be useful for outcomes in relation to the choice of support and advocacy to be considered here as an outcome, particularly for people with disability in regional, rural and remote locations where we know access and choice are difficult.

It is the final outcome in the draft NDAF in relation to increasing community awareness of barriers and stigma that Down Syndrome NSW has feedback on, in terms of elevating it beyond awareness of barriers to a place in line with the social model of disability. The social model of disability fundamentally broadens the focus away from an exclusive concentration on the disease-related physical impairments of the individual to also include the individual's physical and social environments that can impose both disabling limitations and enabling mitigation of limitations.

The social model sees 'disability' is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others.

A social model perspective does not deny the reality of impairment nor its impact on the individual. However, it does challenge the physical, attitudinal, communication and social environment to accommodate impairment as an expected incident of human diversity.

The social model seeks to change society in order to accommodate people living with impairment; it does not seek to change persons with impairment to accommodate society. It supports the view that people with disability have a right to be fully participating citizens on an equal basis with others.

Responsibilities, Reform and Policy Directions (Commitments)

Down Syndrome NSW supports the majority of commitments listed which we have distilled into key themes, namely:

- shared responsibility between states and national government;
- national consistency;
- co-design;
- continuous improvement;
- awareness;
- funding;
- data informed planning;
- interagency communications;
- synergy with Closing the Gap.

Down Syndrome NSW cautions the first commitment whereby the national and state government share responsibility for advocacy. In the past, this has often meant that advocacy can fall between the gaps and is not as well supported as it should be at either level. The ability in the commitments for each advocacy program to be funded, developed and managed by the funding government may create inequities and contradict the following commitment of national consistency and the NDAF itself. We seek that this be carefully considered, articulated and monitored.

Down Syndrome NSW recommends that the following commitments are added:

- accountability: an entity or forum will be established to oversee the implementation and evaluation of the NDAF and the agencies that deliver it, involving people with disability as adjudicators of quality;
- impact and outcomes: will be collected, measured and publicly reported on an annual basis (linking to the existing commitment of data informed planning, which should also be transparent and shared with the sector and community);
- capacity building: sharing best practice, benchmarking, fostering innovation to ensure a strong advocacy sector delivering best possible outcomes for all people with disability, coupled with an understanding of what advocacy is and the types.

Conclusion

Down Syndrome NSW thanks DSS for the opportunity to provide feedback on the draft NDAF. We look forward to the development and release of the workplan as a critical component in the successful delivery of the objective that “people with disability access effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation and inclusion.” We would add to this that advocacy should also build capacity of people with disability, parents, siblings, carers and the community, in line with the social model of disability and person centred approaches.

Down Syndrome NSW welcomes contributing to any working groups that may be established to support the implementation and evaluation of the NDAF.

About Down Syndrome

Down syndrome is a genetic condition, sometimes referred to as Trisomy 21. It is the most common genetic disability. There are approximately 13,000 people in Australia with Down syndrome. The birth rate in Australia for Down syndrome is one in every 1,100 births. Evidence tells us that 9 out of 10 pregnancies in Australia are terminated if Down syndrome is detected.

Most people have 23 pairs of chromosomes, making 46 in total. People with Down syndrome have 47 chromosomes in their cells, having an extra of chromosome 21.

People with Down syndrome have:

- Areas of strengths and other areas where they need support;
- Some level of intellectual disability;
- Some characteristic physical features;
- Increased risk of some health conditions;
- Some developmental delays and learning difficulties.

Down syndrome is a genetic condition, it is not an illness or a disease. It is nobody's fault. There is no cure and it does not go away.

In the 1950's (not that long ago), the life expectancy for people with Down syndrome was as low as 15 years of age. In recent times, progress in medical and social sciences has improved

the quality of life enjoyed by people with Down syndrome. In Australia today, the life expectancy of people with Down syndrome averages 60 years of age.

Whilst this is a milestone to be celebrated, it also presents us with the first generation of people with Down syndrome who will, in the main, outlive their parents. This creates an even greater need for representative associations like Down Syndrome NSW to provide critical services, supports and advocacy at all stages across the lifespan.

With the right supports, people with Down syndrome are able to live full and active lives in their communities. From education, to employment, to community participation, to relationships and housing options, people with Down syndrome enjoy the same needs and aspirations just like everyone else. However, achieving these goals can be harder for people with Down syndrome, with some level of support needed to help them achieve the kind of life that most people take for granted.

Down Syndrome NSW proudly works with passion to support all people with Down syndrome to live inclusive, valued and active lives.

Our Important Work: Down Syndrome NSW

We provide services and supports currently to all people with Down syndrome in NSW, their families and carers across the full lifespan including:

- Information and support;
- Library and resources;
- Workshops and training;
- Parent support networks and regional hubs;
- Prenatal and early years resources and support;
- Inclusive education support, teacher training and behaviour management;
- Transition to school, school years and teens support and advice;
- Post school years transitions including travel training,
- Community engagement and participation for children, teens and adults;
- Accessibility support to participate in events and access infrastructure.
- Health, sexuality and ageing advice, advocacy and support;
- Guardianship and wills resources;
- Self advocacy, capacity building and mentoring;
- Individual advocacy support, advice and resources;
- Systemic advocacy, policy submissions and research.

- Policy, lobbying and proactive government relations;
- Community capacity building, awareness, inclusion and social capital.

We work to promote and represent the views of people with Down syndrome, their families and carers in all that we do. We are governed by a Board comprised of parents and family members, as well as a Down Syndrome Input Council comprised of people with Down syndrome. We hold monthly “Have Your Say” sessions with our adult cohort also to ascertain their views at frequent intervals and undertake robust consultation in a variety of forms to ensure all members have their views heard and represented.

We are enthused to work together with the Commonwealth, state and territory governments to support an inclusive, vibrant and diverse Australia where every person with disability is heard and valued.

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