



Down Syndrome
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Down Syndrome Australia Submission National Disability Advocacy Framework

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Patron: The Governor-General of the Commonwealth of Australia,
His Excellency General the Honourable David Hurley AC DSC (Retd)

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

Down Syndrome Australia and its members work together to provide support for people with Down syndrome and to make Australian society inclusive for people with Down syndrome. We work in partnership to maximise the opportunities and support for people with Down syndrome and their families and support networks.

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 13,000 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: National Disability Advocacy Framework

Down Syndrome Australia (DSA) welcomes the opportunity to provide input on the draft National Disability Advocacy Framework (NDAF). DSA commends the Government on their recognition of the importance of advocacy in protecting the rights of people with disability. We also acknowledge the extensive consultation which has been undertaken on the NDAF, including face to face forums. Our response focuses on advocacy issues as they relate for people with Down syndrome and their families.

Down Syndrome Australia's vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion. In line with the Convention on the Rights of Persons with Disabilities (CRPD) and Australia's Disability Strategy (the Strategy) we work towards a community where all people with disability are included, and their rights respected and protected.

Advocacy is a key way for people's right to be realised. DSA provides national systemic advocacy with and on behalf of people with Down syndrome and their families. We encourage people to utilise individual advocacy where appropriate and we provide self-advocacy opportunities.

DSA also works closely with the other national peak disability organisations and endorses the Disability Advocacy Network Australia (DANA) submission to the NDAF review. Specifically, we commend the recommendations made by DANA to the Disability Royal Commission in relation to independent disability advocacy (Section 5 of the DANA submission to NDAF).

DSA supports the draft NDAF 2022 – 2025, particularly the shared commitment between Commonwealth, state, and territory governments. The objective of the Framework aligns with **our vision of a disability advocacy system that is:**

- fair, equitable, inclusive, and well resourced;
- accessible to people from all disability types including intellectual and cognitive disability, including but not limited to inclusive communications;
- has specialised advocacy services and supports for people with intellectual disability;
- flexible to individual needs and situations including regional and remote communities;
- considers intersectionality and diversity;
- has specialist areas of advocacy for health, justice, NDIS, and other emerging priorities;
- implemented by organisations led by people with disability;
- reflects the social model of disability and a human rights-based approach.

Although DSA supports the intent of the NDAF, we have feedback on some on the content of the Framework.

Principles

Are the principles of the NDAF appropriate?

DSA believes that the NDAF Principles are appropriately informed by the CRPD. There are currently eight principles, which is a lot for people implementing, monitoring, and reviewing the Framework to work within. Consideration could be given to combining some of principles. The points under each principle are long and wordy; we suggest a review of these statements with an aim to consolidate and concretise. The needs of people with complex communication support needs could be better reflected in the principles or elsewhere in the Framework.

Presumption of rights and capacity

- *'All people have the right to respect and dignity'* should be added as first bullet point, in line with CRPD Article 1 Purpose and Article 3 General Principle 1.
- Remove dignity from third point, assuming it is included in new point one.

Access to Support

- This principle is about accessibility, communication and supports. A more suitable name for the principle is *'Access and Supports'*.
- *'Some people with disability need to develop skills and confidence to access advocacy services, self-advocate and be active in systemic advocacy'* should be added.

Participation and Inclusion

- This principle is stated in the Framework's objective. Is it also needed as a principle?

Person-centred Approach

- *'Person-centred approach'* is a disability service delivery model. Change the name of this principle to *'self-determination'* or *'autonomy'* which aligns better with *Nothing about us without us*.

Aboriginal and Torres Strait Islander People with Disability

- This title is not a principle. Is the principle *'Including and Respecting Aboriginal and Torres Strait Islander People with Disability'*? Or *'Align to Closing the Gap National Agreement'*?
- We suggest consulting directly with First Peoples Disability Network and other relevant stakeholders, on the wording and intent of this principle.

Outcomes

Are the outcomes of the NDAF clear and achievable?

Further work needs to be done to ensure that this section provides clear measurable outcomes. The current section includes numerous outcomes, some of which are very ambiguous.

The last outcome listed should be changed to a strengths-based narrative such as *'There is increased community awareness of barriers people with disability face, the benefits diversity of disability brings to humankind and the presence and value of advocacy supports'*.

There should be a statement or explanation around how the Department plans to measure outcomes against this Framework.

It should be noted that these outcomes will not be achieved without adequate funding of the individual and systemic advocacy sectors. To achieve active involvement of people with disability in the programs and services that impact upon them, there must be appropriate support for capacity building and participation in co-design and other activities. For people with intellectual disability, often these opportunities are not accessible or inclusive. Specific funding should be provided to support the involvement of people with intellectual disability in all areas of advocacy and representation (Section 3 of the DANA submission to NDAF).

The important role of systemic advocacy is not well described in the draft Framework. In line with DANA's recommendation for an outcome about systemic advocacy, DSA suggests the addition of an outcome such as '*Systemic advocacy is evidence-based, informed by people with disability and their representative organisations and informs disability and other government policy*'.

Alternatively, the second last outcome could be changed to include specific reference to this.

People with disability have the opportunity to be actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them through systemic advocacy and representative organisations.

Other comments

Do you have any other comments, thoughts or ideas about the NDAF?

Introduction

The first sentence "*Disability advocacy supports people with disability by ensuring their rights are maintained, promoted and valued*" assumes or implies that rights are being met. This is not a reality for many people, and a reason why advocacy is needed. We suggest replacing the word '*maintained*' with '*protected*' or '*realised*'. This will assist with setting the tone of and the need for the framework.

The first paragraph has a focus on individual advocacy. We suggest an additional sentence be added to acknowledge systemic advocacy in the introduction; '*It also involves making changes to laws, policies and systems that impact people with disability*'.

The definitions section on pages 4 and 5 could also be moved up to follow the introduction section.

Implementation

The implementation of the NDAF and the Disability Advocacy Work Plan must be informed by engagement with peak advocacy organisations. The peak organisations must also have a strong presence in the oversight mechanisms of the Framework and Plan.

Definitions

The definition section of the draft Framework needs to be reviewed and redrafted, as recommended by DANA. DSA supports this.

- The Disability advocacy definition needs to be broader and include all elements and scope of advocacy.

- The Self advocacy definition needs to include the activity and impact of self advocacy at a group level.

The definition of systemic advocacy could be improved with the additional explanation described in NSW Ageing and Disability Commission's Review into Disability Advocacy in NSW 2019:

'Designed to provide high quality evidence-based advice to inform the resolution of systemic issues and be particularly informed by the views and lived experience of people with disability'.

Responsibilities

It is not clear how the Commonwealth, states and territories will be made accountable to the Framework and outcomes.

Current and future disability environment

The Framework does not refer to adaptability for unknown future events including pandemics, natural disasters, and changes to policy such as NDIS.

Links to Strategy and Timing

The Strategy Action 5.3 states an Advocacy Framework be developed by 2024. This current Framework is titled 2022 – 2025, but realistically won't start till 2023. The Framework also links to Action 3.3 and ADS Safety Target Action Plan 2021 – 22 to 2023-24 but needs clearer direct links to the whole Strategy, all outcome areas and for the duration up to 2031.

Summary

The National Disability Advocacy Framework aligns with Down Syndrome Australia's vision for a rights based, robust and inclusive national advocacy system. Further review, taking onboard feedback from a range of stakeholders, with subsequent changes and additions will help set the scene, structure, and expectations of the system.

A strong Framework will allow the disability advocacy work plan to build on specific, measurable targets, actions, and outcomes.

In summary, DSA encourages the Government to ensure an advocacy Framework that provides:

- well-funded advocacy services and supports, led by people with disability;
- specific services and opportunities for people with intellectual disability;
- measurable outcomes and robust oversight that includes people with disability and their representative organisations.