

Review of the National Disability Advocacy Framework (NDAF) April 2022

Submission from the Down Syndrome Association of the Northern Territory Inc. (DSANT)

Thank you for providing this opportunity to contribute a submission to the National Disability Advocacy Framework (NDAF). This submission is in three parts:

1. Statement about the role of the Down Syndrome Association of the Northern Territory Inc (DSANT).
2. Consultation and response by adults living with Down syndrome and intellectual disabilities who attend Project21, the post-school adult learning centre for people with Down syndrome and intellectual disabilities run by DSANT.
3. Submission by DSANT drawn from the students and DSANT's experience of working with its clients and advocacy services.

1. Statement about the role of DSANT

The Down Syndrome Association of the Northern Territory (DSANT) is a for purpose Association providing peer support, resources and educational programs for people with Down syndrome and their families across the NT. Membership spans across the life continuum, from pre-birth to aged care and services are available to extended network of supports such as school personnel, medical services, extended families, and the wide range of service providers and associations in the disability sector (Government, non-government and private providers). Since 2015, DSANT includes an element of service provision through the NDIS with specific focus on post school adolescents (18 to 25+ years) transitioning through pathways of support toward independence, employment and education.

DSANT makes it a priority to inform and educate its clients, their families and our staff about human rights and service standards. Advocacy is an important way that people with an intellectual disability can assert their rights and be included in Australian society.

1. Consultation and response by adults living with Down syndrome and intellectual disabilities

Process: Three students and a teacher participated at the NDAF consultation in Darwin on 17 June and reported back to their college class in Project21. Five students then discussed and prioritized the goals listed in the Easy Read version of the draft framework.

Students' responses:

We read and discussed the goals for disability advocacy in the Draft National Disability Advocacy Framework 2022-2025 Easy Read version.

The students said the most important goals for disability advocacy are that people with disability have:

The **same rights** as everyone else and this includes being able to live independently

Advocacy so they can **make their own decisions**, those decisions could be to go on holidays, to move out of their parents' house or to have children.

Support if they have been abused or neglected. The group felt very strongly about this.

The chance to **ask for what they need and feel supported** to get it. The example was to be able to travel independently

Legal advice if they need it, this should include an advocate go to the police with a person.

Advocacy, even if they live far away because people with a disability live in rural and community areas and those people have medical and educational rights that require advocacy support.

A community that listens and learns about disability. One of the DSANT students gave a talk about his disability to his work mates on the International Day of Disability. People talked to him about it afterwards and said it was new information for them and they thanked him.

Services that use what people are good at to help them make decisions and to help them explain their problems. The example given was that a person with a disability had videoed themselves talking about their problem and sent the video to an advocate. It was much easier for that person to talk than to write, so it would be good if advocacy services can take information in a video, not just email.

Inclusion in the community. This includes work and social life.

Respect, regardless of their age, culture, if they are First Nations people or LGBTQI+ **Their say** in the community and can tell government what they need.

2. Submission by DSANT

We have used the questions provided by the Department to structure our submission.

Do you believe the new NDAF encompasses your vision of advocacy? If not, what changes are required?

DSANT agrees strongly that advocacy services should be nationally consistent and of a high-quality.

Our vision is a society that understands people with a disability have the same human rights as everyone else and that is inclusive of people with a disability. Achieving this vision requires effort from everyone, including the advocacy sector.

Government and the advocacy services must go beyond providing services to individuals with a disability and prevent rights issues from arising in the first place. It's not enough to have advocacy services that wait for calls for help. It's good to see that under the heading of

‘listening to people with disability’ that helping people ‘speak up and learn...and do things for themselves’ is included.

Advocacy services need to have the capacity to be pro-active, educating people with a disability and more importantly the whole community.

A related issue is that many community-based groups are now service providers under the NDIS. They cannot provide much education and training on rights without it being a conflict of interest. The pool of appropriately placed organizations to provide such training to individuals and to informal advocates such as friends and family is very small and the demand for such education should be large.

Our vision is that community-based education and training is specifically supported in funding agreements to paid advocacy services. This training component would be consistent with the principles and outcomes of the NDAF.

The NDAF focuses solely on paid advocacy services; its intersection (and often reliance) on informal advocates is not mapped. Much of the advocacy for people with an intellectual disability is done by family and friends. The NDAF does not encompass this critical dimension of ensuring that the rights and needs of people with disability are met.

The changes that we believe are required are to add in support, training and education for informal advocates. These parts of the advocacy framework should be valued and supported. Effective rights-based advocacy requires skill and knowledge (e.g. understanding conflict of interest). This is capacity building for the community and ultimately leads to better outcomes as problems can be addressed at a local level and before there are entrenched practices that contravene Codes of Conduct and human rights.

Are the principles of the NDAF appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

The principles are written with individuals in mind, which is understandable and respectful of their human rights. However recent changes to the systems that impact on people with disability, such as the implementation of the NDIS mean that systemic advocacy can be the most effective path to solve problems. A problem with the NDIS may affect many people spread across Australia and not every person with a disability has the capacity to self-advocate or find a paid advocate. In these situations, systemic advocacy needs to be available.

Our vision for the NDAF explicitly describes how systemic advocacy is part of the Framework.

Are the outcomes of the NDAF clear and achievable? Should different ones be included? If so, what should be included?

The draft outcomes for the NDAF are clear. They will only be achievable if the disability advocacy sector has considerably more funding than at present.

Are the responsibilities, reform and policy directions of the NDAF relevant or should different ones be included?

The first of the Draft Commitments is ‘shared responsibility across governments for making sure that there is effective disability advocacy’. This change is in the context of national

requirements such as the NDIA's Quality and Safeguarding Framework. It will be difficult to set up a simple system of administration for advocacy services that is transparent and accountable. How will checks, balances and obligations on services be carried out and by whom? Complex administrative requirements take resources away from direct service provision.

Our vision is a simple, transparent system of administration and accountability.

Does the NDAF identify what's needed in the current and future disability environment? If not, what changes are required?

People with a disability are living longer than in decades past. For people with Down Syndrome aging may include early onset dementia, such that a younger adult requires services that usually accompany old age.

The NDAF should formally consider how the disability advocacy services will mesh with aged care advocacy so that people with a disability continue to have their rights respected and enjoy full and inclusive lives in the community.

Submission collated and produced by Rachel Kroes, CEO of DSANT, and Deborah Hall, Lecturer Project21, on behalf of the Down Syndrome Association NT Inc

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