

Submission
To the review of the National Disability Advocacy
Framework

About the NSW Disability Network Forum

Initiated in June 2011, the NSW Disability Network Forum (the DNF) comprises non-government, non-provider peak representative, advocacy and information groups whose primary aim is to promote the interests of people with disability. The aim of the NSW Disability Network Forum is to build capacity within and across all organisations and groups so that the interests of people with disability are advanced through policy and systemic advocacy. The Council of Social Service of NSW (NCOSS) provides secretariat support to the DNF.

NSW Disability Network Forum Member Organisations:

Aboriginal Disability Network NSW	Multicultural Disability Advocacy Association of NSW
Association of Blind Citizens of NSW	NSW Consumer Advisory Group - Mental Health
Brain Injury Association NSW	NSW Council for Intellectual Disability
Deaf Australia NSW	NSW Disability Advocacy Network
Deaf Society of NSW	People with Disability Australia
DeafBlind Association NSW	Physical Disability Council of NSW
Deafness Council (NSW)	Positive Life NSW
Information on Disability and Education Awareness Services (IDEAS) NSW	Self Advocacy Sydney
Institute For Family Advocacy	Side By Side Advocacy Incorporated
Intellectual Disability Rights Service	Council of Social Service of NSW

Introduction

The DNF welcomes the opportunity to input into the review of the National Disability Advocacy Framework (the Framework). As the discussion paper notes, it is timely to review the Framework in light of the roll-out of the National Disability Insurance Scheme (NDIS) and the implementation of the National Disability Strategy.

The DNF strongly supports the Principles, Outcomes and Outputs of the current Framework. However members note that, while advocacy is a crucial factor in enabling NDIS participants to achieve choice and control, it is also central to the inclusion of people with disability who are not eligible for the NDIS. Further, to achieve equity and improve the lives of people with disability, it is critical that advocacy be adequately funded.

The NSW Government has committed to handing over 100% of the funds it currently directs to disability to the Commonwealth National Disability Insurance Agency (NDIA) by 2018. This includes the money that funds advocacy organisations to undertake a range of activities both related and unrelated to the provision of disability services. These organisations only have certainty of funding until June 2016. After this time, the NSW Government may withdraw funds if Commonwealth funded services duplicate the organisation's activities.

Accordingly, it is important that this review consider a broader context than how the NDIS impacts on the provision of advocacy. While the NDIS is important, the DNF believes the Framework should

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aim for greater inclusion of and responsiveness to people within disability within and outside of a service framework.

This submission will briefly examine the importance of advocacy, noting the expanded role of the Commonwealth in advocacy provision due to:

- the NDIS transition process and NSW Government withdrawal of support for state-based disability advocacy; and
- the introduction of frameworks such as the NDIS Quality and Safeguards Framework which require advocate services to play an integral role in their success.

This submission will then make comment on some of the Principles and Outcomes in the Framework— emphasising the importance of independent advocacy and areas where the components of the Framework may need greater integration.

Importance of advocacy

The NDIS paradigm involves inclusion in the community as a whole and access to mainstream, rather than disability specific services. This will take a concerted effort from all stakeholders and information about what works and what needs improvement will be key to guiding this process. Services that provide independent advocacy, representation and independent information need to remain in this landscape, working collaboratively with all levels of Government so people with disability get the best outcomes from this period of change.

Independent advocacy is crucial because of its unique features including:

- linking people with information services that can assist people with disability;
- acting as an ‘early warning’ system, allowing issues to be handled with expertise at an early stage, and avoiding costly escalation;
- standing beside vulnerable individuals and groups and taking necessary action to defend and protect their rights and interests, while maintaining their integrity by avoiding conflicts of interest. Many people with disability and their families do not have the capacity, knowledge or skills to advocate on their own behalf without support, particularly if they face language or other communication barriers;
- helping to build the capacity of people, families and citizens to advocate for themselves, their family member, or fellow citizen; giving them a ‘voice’ in decisions that affect their lives;
- making contributions to public policy debates on behalf of people with disability and working for systemic change across all areas of government, business and community life to break down barriers and improve the lives of people with disability; and
- raising government, service provider, family and general community awareness about the rights and interests of people with disability, and identifying barriers and opportunities for improvement.

Locally based advocacy organisations are particularly important because:

- they are knowledgeable and connected with service providers and government agencies at the local level; and
- they can tap into the pool of local volunteers for many roles, thus making funding more 'value for money'.

The Victorian Ombudsman has recently highlighted the benefits of independent advocacy in terms of protecting people with disability from abuse, noting there is an unquantified gap between those who would appear to need advocacy and those who receive it.¹

Advocacy services need to be properly funded

Inadequate resourcing of advocacy has been a key inhibitor of the sector in terms of achieving desired outcomes. This situation has been paralleled in England, where the Commission for Social Care Inspection noted in its 2008 report² that although advocacy was highly valued and achieved results for vulnerable people, 58% of Councils inspected experienced shortfalls in advocacy funding, meaning that people with disability had been turned away. Likewise, DNF members report a substantial amount of unmet need, taking on clients of other services with waiting lists of eight weeks to one year.

Unmet need in the Deafblind community include lack of trained support workers to address unique needs deafblind people have when accessing the general community. Many people do not have the level of sight or vision required to access the community, or communicate without assistance. Other countries have communication guides for deafblind people to provide this important support, such as the Canadian Deafblind Association in Ontario.³

The NSW Government currently provides approximately \$10 million p. a. to services that provide disability advocacy, information and representation. The DNF understands that NSW is one of the only states that will not continue to fund some residual state-based disability services after the NDIS is implemented. This is deeply concerning, leading to a real risk that advocacy services will be rationalised or discontinued, leaving people with disability vulnerable as they navigate a new system. Further, funding uncertainty will force experienced staff to leave the sector, meaning that significantly less expertise and local knowledge – which advocates have built up in local communities over decades – will be available to assist people with disability in the new environment. This local knowledge is organic and will take time to rebuild if the sector is weakened. In addition, as explored

¹ Victorian Ombudsman, (2015) "Reporting and investigation of allegations of abuse in the disability sector:Phase 1 - the effectiveness of statutory oversight", at [523], available at https://ombudsman.vic.gov.au/VO/media/VO/Parliamentary%20Reports/HTML/web_VO-Report_Disability-P1.html#nExecutiveSummary

² Commission for the Social Care Inspection (2008) *Safeguarding adults A study of the effectiveness of arrangements to safeguard adults from abuse*, London, p. 3 (available at <http://www.elderabuse.org.uk/Documents/Other%20Orgs/CSCI%20Report%20-%20safeguarding.pdf>)

³ Canadian Deafblind Association, Ontario Chapter, see http://www.cdbaontario.com/services/training_e.php

below, the Government will be left without an essential source of advice, input and support in the implementation of their broader disability inclusion agenda.

To ensure the success of the NDIS and National Disability Strategy, it is essential that people with disability in NSW continue to have access to advocacy and representation services, and that their access is not constrained by rationalisation. It is therefore critical that at a minimum, the Commonwealth carefully assesses which services will continue to be provided under the Information, Linkages and Capacity Building Framework and which may be left unfunded. If this does not occur, there is a real risk that advocacy services in NSW will be rationalised, specific funding will be lost and people with disability encountering difficulties will have no avenue for assistance and support.

The DNF sees advocacy as an integral partner to the success of new initiatives such as the NDIS Quality and Safeguards Framework. The potential of these frameworks to respond to vulnerable people may be hampered if this partnership is unsupported — especially in the early phases of implementation where understanding of systems will be low.

As people with disability experience greater choice and control and deeper interaction with mainstream services, the need for advocacy is also likely to increase, particularly in the initial phases of the reform. For example, as people are given greater choice in areas of their life such as housing and leisure activities, they may experience exclusion or discrimination which the assistance of an advocate could mitigate.

Recommendation 1

That the Australian Government ensure current levels of funding for advocacy in NSW are not reduced in the transition to the NDIS. At a minimum, funding must be equal to the current investment from the National Disability Advocacy Program (NDAP) and the NSW Government

Current arrangements for advocacy under the NDIS

The Disability Reform Council Communique of 24 April 2015⁴ outlined that some supports related to individual advocacy such as decision support, safeguards support and support to approach and interact with disability and mainstream services would be funded by the NDIS either through individual packages or through a revised Information, Linkages and Capacity Building policy framework. The Communique did not provide detail about the scope of this funding.

The DNF emphasizes that ‘decision support’ is different to individual advocacy. For example, a person with intellectual disability evicted from their home needs individual advocacy to negotiate the system to find crisis accommodation, appeal and/or find a new home. This will need to happen by working closely with the person. While supported decision making may be part of this process, other aspects such as research, assistance filling out paperwork and meeting other expectations of

⁴ COAG Disability Reform Council Communique <http://mitchfield.dss.gov.au/media-releases/coag-disability-reform-council-communiqu>

setting up a new tenancy are not going to be met by decision supports alone.

The DNF also notes that its ability to provide a definitive response to the Disability Advocacy Framework is hampered by the fact that the NDIA's vital Quality and Safeguards framework is still in development. As such, the DNF believes it would be advisable to review this Framework after the component parts of the NDIS have been finalised. This would allow for an assessment of how well intersecting parts of the system work together to create positive outcomes for people with disability. Furthermore, any gaps identified by the process could be addressed at an early stage.

Advocacy outside the NDIS

The National Disability Strategy sets out six priority areas for action to bring about change in mainstream services and community infrastructure, and improve the lives of people with disability, namely:

- inclusive and accessible communities;
- rights protection, justice and legislation;
- economic security;
- personal and community support;
- learning and skills; and
- health and wellbeing.

These focus areas do not relate to the NDIS but to the interaction of people with disability with mainstream services. Likewise, the majority of the work of advocates relates not to disability services but to assisting people with disability navigate services such as the health, housing, education and justice systems, and suggesting ways in which these systems can be more accessible, responsive and inclusive of people with disability.

This is illustrated by the following example:

An advocate helps a man with an intellectual disability who has been living independently in social housing, with the process of moving house when the landlord wanted to sell the property. This included explaining to him why he had to move, negotiating on his behalf with Housing NSW, assisting him with the process of signing a new lease, and guiding him through tasks that have to be done when a person changes address and what to do if there is a problem with any of the neighbours.

Other policy areas outside the NDIS demonstrate a clear need for disability advocacy. For example:

- The *Disability Inclusion Act 2014* (NSW) mandates that government agencies consult with people with disability in the development of their Disability Inclusion Action Plans. Advocacy organisations can assist to fulfil this role because they are well placed to learn from the collective experience of their members and identify trends in areas working well or needing improvement and then represent these trends to Government;

- In its recent inquiry into young people with disability in residential care, the Senate Standing Committee on Community Affairs recommended that all people with disability under 65 in residential care, or at risk of entering residential care be assigned an advocate to provide them – and their families – information about their options and act for them if appropriate.⁵ This recommendation is to be applauded; its implementation will require significant advocacy resources.

Recommendation 2

That advocacy must be sufficiently resourced to enable the Commonwealth and NSW policies and programs relying on it – such as those identified above – to be implemented as intended, giving voice to people with disability.

Comment on Principles

- **Disability advocacy ensures that views represented meet the individual preferences, goals and needs of people with disability**

For this principle to be achieved, it is important that organisations other than peak bodies are funded. Membership organisations are able to gain access to a 'grass roots' perspective of issues facing people with disability and develop policy positions based on individuals' experience. Peak bodies are a step away from individuals, and are less able to represent 'individual needs, goals and preferences' but are invaluable in identifying trends and pushing for systemic reforms.

In addition, an organisation's 'peak' status is derived from its relationship with member organisations. If member organisations ceased to exist in the advocacy landscape, 'peak' organisations would lose their capacity to engage broadly on a range of issues and work with members to create systemic change for the benefit of people with disability and Governments.

- **Disability advocacy recognises and respects the diversity of people with disability**

The DNF supports this Principle, and believes it needs to be reflected in the Outcomes or Outputs of the Framework if it is to achieve real action for people with disability. Aboriginal and Torres Strait Islander (ATSI) people with disability and those from culturally and linguistically diverse (CALD) backgrounds face systemic disadvantage and exclusion yet there is minimal funding attached to working respectfully with these communities and responding effectively to their needs.

Additionally, deafblind people (who have a combined vision and hearing impairment) cannot rely on generic advocacy because of their specific communication needs. Auslan is only used for people who have grown up in the Deaf community, there are a variety of communication methods used by people who have lost hearing later in life or who are congenitally deafblind. Without specific

⁵ Australian Senate, (2015) "Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia", Senhoseate Printing Unit, Canberra, p. 104.

Deafblind advocacy, people who are deafblind will continue to be treated as being unable to communicate because of profound intellectual disability instead of lack of hearing and sight.

Recommendation 3

That advocacy is resourced at levels that allow it to be accessible to people with specific communication needs.

Comments on Outcomes

Independent advocacy free from conflicts of interest

The DNF commends the fact that systemic advocacy will be funded outside of the NDIS. This is in line of the Productivity Commission's 2011 recommendation, which recognised that relying on an individual's capacity to privately pay for systemic advocacy is likely to render it unobtainable to the most vulnerable, who need it most.

It is also crucial that individual advocacy be independent of service provision, so that people with disability can receive impartial assistance to navigate their supports. As highlighted in this submission, the ability to hold service providers to account is a crucial feature of independent advocacy.

This point is highlighted by the Victorian Ombudsman, who states that:

Advocacy services, and the funding of advocacy, should be independent of all agencies involved in funding, regulating, or providing services to ensure they can be truly fearless when standing up for the vulnerable.⁶

The importance of independent advocacy is highlighted by the following case studies from DNF members.

Advocates have assisted people with disability in meetings and negotiations to change service providers. It is very unlikely that the service provider would have initiated this process, which could result in its funding being withdrawn and paid to another service. Conflicts of interest would be likely to stop service performing this

Although individualised funding will be available under the NDIS, people may need independent assistance to argue for the separation of accommodation and support.

⁶ Victorian Ombudsman, note 1, at [19].

An advocate has been supporting a young man with intellectual disability and autism who lives at home with his mum. The man does not speak. However, it has become clear through therapy that he has a good understanding of what is going on around him and he has begun to communicate using a keyboard.

The client's mother had unsuccessfully appealed the Community Participation decision twice. The advocate organised a successful appeal so that the service provider of the man's Community Participation program was compelled to provide an additional computer and to set aside time each day to support him in improving his communication using the keyboard. He is now making improvements.

A man was morbidly obese, had an amputated leg, and suffered from schizophrenia. The service ceased support due to the fact that the man was a smoker, and the service felt this was a work health and safety issue. The advocate, with both the parent and the consumer's permission, sought an explanation from the service provider as to why they were not supporting the man, and asked how they were using the funding. The service could not give a credible explanation.

The advocate took the matter to the funding body to find out how the service could be resumed as quickly as possible. The advocate suggested using some of the funding to install an extractor fan to remove the tobacco smoke. Further, the advocate engaged the community Occupational Therapist who conducted an assessment and a new reclining wheelchair and shower commode was obtained. The advocate also communicated with the Department of Housing to gain approval for the extractor fan to be installed. Eventually this was done and the service was resumed.

Deafblind Services lobbied for the introduction of appropriate communication training in group homes. Prior to this, staff had been trained in sign language, which is inaccessible to deafblind people. In houses where Deafblind Services had given communication training, the quality of lives has improved and, according to staff, "behavior problems have disappeared".

Comments on Outputs

- **Disability advocacy that is planned and delivered in a coordinated manner and supports communication between disability advocacy support, disability services, mainstream services and governments**

This Output does not take account of the fact that much individual advocacy is an emerging response to people in crisis. For example, an advocate may be called to assist a person facing immediate eviction, or to support a person at a police station or in Court.

The DNF is concerned that advocacy that requires an immediate response will be underfunded in NSW if NDAP is not expanded to take account of the fact that the NSW Government will no longer fund these activities once full implementation of the NDIS has occurred. This could mean a seriously increased risk of harm from a range of undesirable outcomes such as homelessness, wrongful imprisonment and poor health outcomes for an already vulnerable group of people.

NSW DISABILITY NETWORK FORUM

The DNF recommends that NDAP contracts be drafted flexibly, enabling organisations to be responsive to need, rather than being constrained by particular 'deliverables'.

While crisis response is vital to improving short-term outcomes for people with disability, it is valuable to have a peak body, such as Disability Advocacy Network Australia (DANA), to highlight opportunities for systemic change, notice emerging trends and link into and commission research on best practice that will benefit people with disability. This focus leads to better long-term outcomes for people with disability and assists Governments to design programs and policy on the basis of informed and targeted input.

Recommendation 4

That NDAP contracts be drafted flexibly, enabling organisations to be responsive to need, rather than being constrained by particular 'deliverables'.

Recommendation 5

That the NDAP fund a peak advocacy body to undertake functions such as highlighting opportunities for systemic change, recording emerging trends and linking into and commissioning research on best practice that will benefit people with disability.