



**Brain Injury Network
of South Australia Inc. (BINSa)**

Submission:

**Brain Injury Network of South Australia Inc. (BINSa)
Review of the National Disability Advocacy
Framework (NDAF)**

Executive Summary

BINSA is recognised as the peak body in South Australia for people with an Acquired Brain Injury (ABI), and is pleased to provide a submission to the Department of Social Services (DSS) for this important review of the NDAF.

BINSA is funded by the DSS under the National Disability Advocacy Program (NDAP) to provide individual advocacy (85%), family advocacy (5%), self advocacy (5%) and systemic advocacy (5%). It is also funded by DSS to provide the support component for the External Merits Review Supports Service (EMRSS) for people seeking a review of NDIA decisions in the Administrative Appeals Tribunal (AAT). BINSA receives some funding from the SA Government to provide counselling, community learning, office facilities, and a 'Springboard' program. The Motor Accident Commission funds a Reconnect Transition Program. It should be noted that the SA Government has not provided funding to disability advocacy services in SA for many years.

BINSA's comments within this submission are based on input from BINSA advocates, board members (including a person with a disability), and management.

Of course, all of what has been achieved is made possible by sponsorship. We are hugely appreciative of MAC's ongoing support, and thrilled to have the opportunity to continue this crucial work throughout 2015–16 and beyond.

Nahtanha Davey

Chief Executive Officer

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Introduction:

The Australian Government Department of Social Services (DSS) is reviewing the NDAF and asking for submissions to help inform development of the new Framework. DSS has made available a Discussion Paper to use as a guide when developing submissions, and has advised that reviews will be conducted in line with the principles of the National Disability Agreement (NDA) and the National Disability Strategy (NDS).

1. Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?

1.1. Partnerships

The current Framework has provided a sound basis to enable and support people with disability to protect their rights and overcome barriers, though requires some enhancements to recognise the essential role that advocacy will play to facilitate true empowerment of people with disability within the NDIS environment. This builds on the focus on partnerships within the National Disability Strategy (NDS) and the National Standards for Disability Services (NSDS), which emphasizes the importance of people with disability participating in decisions that affect their lives along with family, friends, carers and advocates. Both the NDS and NSDS promote active participation in decision making to safeguard and advance the human rights, wellbeing and interests of people with disability. The NDIS environment is a paradigm shift in the way services are provided to people with disability. The person centred approach of the NDIS provides that people with disability are now considered to be in the driving seat, and it is necessary to not only transfer the necessary resources to the control of individuals, but also to work hand in hand with people with disability and their families/friends/carers – and advocates - to ensure the process is effective and enabling at every stage.

1.2. Definition of Advocacy

The definition of Advocacy which is provided within the Discussion paper (page 2) is not considered to adequately reflect advocacy as it currently exists, or within the NDIS environment. The reference to advocacy supporting people with disability to 'find employment and training' is not accurate, as this is outside the scope of advocacy and is a form of employment service provision. The definition of Advocacy also does not focus on the preventative role which disability advocacy plays in the area of human rights, as well as early intervention, which ideally works towards minimizing risk and often resultant crisis strategies.

The definition of advocacy which was provided in the full version of the NDAF (Clause 9, page 2), is considered reasonable, and the explanation of advocacy in the National Disability Strategy (page 17) is felt to be valid, and particularly relevant to the NDIS:

"It is important that people with disability have the opportunity to participate in decisions that affect their lives. For some people this participation is supported by advocacy services.

Disability advocacy enables and supports people with disability to safeguard their rights and overcome barriers that impact on their ability to participate in the community. Advocacy

supports people to make sure that their rights are promoted and valued, to participate in the decisions that affect their lives, especially around access to services and support, and to be actively involved in the life of their communities. Disability advocacy enables people with disability to actively participate in the decision-making processes that safeguard and advance their human rights, wellbeing and interests.”

BINSA is supportive of maintaining the two streams of advocacy – Individual and Systemic - which will be both critical and inter-related to the NDIS. To be most effective, Systemic advocacy needs to have good linkages with individual advocacy to enable a flow through of information about the key issues affecting people with disability.

1.3. NDAF Vision of Advocacy

It is timely to develop a vision of advocacy, which maintains a focus on protection of human rights (in line with the United Nations Convention on the Rights of Persons with Disabilities), but with a strengthened focus on the role disability advocacy can provide for people to meaningfully participate in decisions that impact their lives – this role will be critical if the person centred focus of the NDIS is to be achieved. The intention of person-centred approaches is to maximise, as much as reasonably possible, the capacity for people with disabilities to take control of their lives.

Person-centred approaches ensure that individuals are in the centre of service design, planning, delivery and review. Advocates can support individuals shape and direct service and support arrangements to suit their strengths, needs and goals.

A vision could be along the lines of:

“People with disability have access to individualized disability advocacy that promotes, protects and ensures their human rights, empowers people with disability to take control of their lives, make informed decisions and fulfill their potential as equal citizens in an inclusive Australian society.”

1.4. Planning and Decision Making within NDIS

Within the NDIS environment, disability advocacy can help people to understand their rights, make choices, navigate service systems, support people with internal NDIS complaints/review mechanisms. Disability advocacy could also play a role in supporting people prior to the initial contact with the NDIS, for example to discuss and identify what may be considered ‘reasonable and necessary’ for an individual’s plan, what is realistic/achievable, what may be appropriate goals, start to think about supports before they meet with the NDIA planner. Many people with ABI have limited relationships with family and/or friends, and so do not have natural safeguards/support to work through these issues. It is important to develop trust with people with ABI (many of whom have complex needs, and often triple diagnoses including physical and mental health issues). Time spent with an advocate prior to contact with the NDIA (as well as at the actual planning meeting, subject to consent of the individual) would be of benefit to both the individual and the NDIA planner to ensure a positive outcome. BINSA is aware of a number of existing clients who need patience and time to ensure they are listened to appropriately and their needs are met. Recently one client refused contact with a Disability SA worker, who repeatedly said, “I understand”, when the client clearly believed the worker had no understanding. This type of incidence could occur within the NDIS environment if people with ABI are not adequately supported by trained and skilled disability advocates.

1.5. Self Advocacy within NDIS

BINSA recognises that individual capacity building (using self advocacy in some cases) will be important for many NDIS participants, and could be a valued role for many disability advocacy services. However, in the case of ABI, Self advocacy is unlikely to be an achievable outcome. The nature of ABI means that many people will have permanent memory and concentration issues, and are likely to always need ongoing support and/or advocacy, particularly in the implementation and review of a NDIS plan. BINSA believes that capacity building with families and/or carers (if available), and with communities is equally as important to ensure that society more broadly understands ABI and can work collaboratively to fulfill responsibilities.

1.6. Systemic Advocacy

BINSA is strongly supportive of systemic advocacy, and believes this is the responsibility of all disability advocacy agencies. Enhanced collaboration across disability advocacy agencies and key stakeholders is essential to promote true systemic action at the state and national levels. BINSA is in the initial stages of developing a disability advocacy network in South Australia to promote collaboration, with a view to ultimately identifying trends and issues at the systemic level.

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

- 2.1. BINSAs believes that an additional Principle is required to focus on the important role which disability advocacy can play in community capacity building.

Achieving the goals of the NDIS will require community development, building social capital, community education, and valuing the contribution that people with disabilities can make in their communities. Mobilizing social capital can create opportunities for people with disability to experience social and economic participation through engagement with mainstream services. By being intentional about engaging community networks and creating the time and space for people with disabilities and their families to be actively involved, pathways to participation, inclusion and citizenship are facilitated.

Sector development requires challenging people's expectations for what people with disability can achieve, including the broader community, the private sector, government, services, families and the person with the disability themselves.

Community capacity building should aim to improve the community inclusion experience of people with disabilities. At its most effective, community inclusion has benefits for the whole community, in that all people benefit from a community, which celebrates diversity and protects and promotes the rights of all people. Investing in community awareness and capacity building will create opportunities for the social and economic participation of people with disability, their families and carers, improving personal outcomes and strengthening the connection between people with disability and their communities.

- 2.2. BINSAs believes that there should be a stand alone Principle reflecting the person-centred focus of disability advocacy. Disability advocacy should be tailored to the individual needs of the person with the disability, which means that in the case of ABI, a 'specialist' form of disability advocacy is required rather than generalist disability advocacy. BINSAs has had clients referred from other disability advocacy agencies who do not have the expertise and skills to adequately work with the needs of people with ABI.

- 2.3. BINSAs's response to Question 1 above indicates that self-advocacy may not always be the most appropriate option for people with ABI. BINSAs recommends that the sixth Principle be amended to add "encouraging self-advocacy where possible".

- 2.4. BINSAs acknowledges the value of peer support, which is facilitated by advocacy, and believes that this could be an addition to the fourth Principle to therefore read: "Disability Advocacy promotes peer support, leadership and capacity building by people with disability"

- 2.5. In the changing disability environment, BINSAs recommends that the ninth Principle also include collaboration in addition to strategic alliances, as a requirement. Collaboration is a way of enhancing capacity, and working towards a common purpose or vision, which should be around protecting and ensuring human rights for people with disability.

3. Are the outcomes of the Framework still relevant or should different ones be included? If so, what should be included?

- 3.1. BINSAs recognise the importance of having achievable and measurable outcomes, which are regularly monitored, evaluated and reported upon. This type of accountability would be a valuable tool to identify trends and priorities for systemic advocacy. Historically, these NDAF outcomes have not been reported upon at the state/territory or national level. All outcomes should be carefully reviewed to determine exactly how they can be measured, and have a relevant output measure.
- 3.2. As with our comments on the definition of advocacy (see above), it is not the primary role of advocacy agencies to support people with disability to achieve economic participation (2nd Outcome), and this outcome could be reworked to have an overall focus on social inclusion and community participation, which by its nature can include economic participation where appropriate.
- 3.3. There are some existing outcomes which are general enough to cater to a potential new role for disability advocacy within the NDIS, particularly the third and fourth dot points, however these again could be strengthened, or alternatively specific outcomes developed which are tailored towards outcomes for the NDIS environment, e.g.: “people with disability have the opportunity to receive independent advocacy support at all stages during the NDIS process”; “people with disability receive independent advocacy support to develop individual capacity and self-advocate where possible”.
- 3.4. As with our earlier comments, we firmly believe that individualized advocacy support from advocates trained and experienced in ABI is essential. Accordingly, we could recommend that the fifth dot point include a focus on ‘individualised’ independent advocacy support.
- 3.5. The 7th dot point could be amended to say “people with disability are given opportunities to be actively involved”, as it is our experience that not all people wish to be involved for a variety of reasons.

4. Are the outputs of the Framework still relevant or should different outputs be included? If so, what should be included?

- 4.1. Successful delivery of outputs will be contingent on appropriate and equitable funding to disability advocacy agencies nationally. In the case of South Australia, there has been no State Government advocacy funding for many years.
- 4.2. It should be noted also that the original National Disability Strategy considered that there be “provision of funding increases to advocacy agencies ... to participate in monitoring and evaluation of the strategy”. BINSAs are obviously keen to collaborate with government and key stakeholders to consider ways of promoting efficiencies and sustainability, however a sizeable increase in disability advocacy funding will be required to address the huge numbers of people who will be eligible to receive NDIS plans, and who elect to receive disability advocacy support. In South Australia, adults are not yet part of the NDIS implementation, and we anticipate a massive request for advocacy support when the scheme is progressively rolled out from 2016.
- 4.3. Consistent with the National Standards for Disability Services, we strongly support continuous quality improvement, and believe there should be an Output measure addressing this area. Consistent with this, the second dot point could be amended to include: “Disability advocacy that is informed by feedback from clients, an evidence base and is provided in an accountable and transparent manner, and used to inform best practice”.
- 4.4. Consistent with earliest comments about the potential role of disability advocacy agencies in community capacity building, the fourth dot point could read: “Disability advocacy that promotes capacity building of communities, community education and awareness of disability issues and rights, and the strengths/abilities of people with disability”.
- 4.5. A specific Output(s) tailored to how disability advocacy will support NDIS clients would be useful, for example: “Individual advocacy that supports NDIS participants at all stages of the NDIS process, including provision of information about rights, choices, service options”.

5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?

5.1. BINSAs believe that the Framework needs to be underpinned by a culture of continuous improvement to ensure that disability advocacy services are managed effectively and efficiently, that services are person-centred, with flexibility to respond to individual strengths and needs using contemporary practice. A focus on quality management principles (sound governance and management, clear communication, continuous improvement and evidence based practice, collaborative partnerships, active participation of people with disability etc.) will promote efficient, sustainable, accountable disability advocacy services, which maximise outcomes for people with disability using advocacy support.