Review of the National Disability Advocacy Program

21 June 2016

Synapse / Brain Injury Association of NSW (BIA), is the peak advocacy body in NSW for people with a brain injury (BI), their carers and family members.

We are well engaged with our membership, stakeholders and have a good understanding of the key issues facing people affected by BI in NSW.

This submission is informed by BIA’s advocacy work with people who have a BI, their families, carers, providers or other services/supports and is based on the questions proposed by the discussion paper.

Initially we would like to thank the Department of Social Services for requesting submissions and acknowledge that the following objectives remain paramount in assisting people with a disability:

The objective of the NDAP is to ensure people with disability are provided access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation.

NDAP agencies receive funding under the *Disability Services Act 1986,* so they can provide disability advocacy support using a disability advocacy support model.

Disability advocacy support models are focused on individual advocacy, systemic advocacy, citizen advocacy, family advocacy, self advocacy and legal advocacy.

In addition to providing one or more of these models of disability advocacy, NDAP agencies may also be funded to specialise in providing advocacy support to:

* people from Aboriginal and Torres Strait Island families or communities;
* people from diverse cultural and linguistic backgrounds; or
* people with a particular disability type, for example, an acquired brain injury.

We are currently funded to provide advocacy services to people with a brain injury in NSW.

We receive funding for the equivalent of one full time advocate to provide services to an estimated 400,000 people whom are affected by brain injury. We provide individual and systemic advocacy.

In preparing our response to the NDAP Review, we have reviewed other organisations’ submissions, plus we are party to the submission by the NSW Disability Network Forum and as such we do not wish to repeat the comments included in those submissions, but rather to highlight specific areas relevant to our organisation.

As a Peak organisation in NSW and with a recent merger with Synapse (Brain Injury Association of Queensland) we have over 1,200 members who we consult to provide comment to government and policy makers. Peak bodies have a mechanism for the capturing of trends as well as identifying human rights and service access issues within the disability services sector. Identification of the network of advocacy services within the community disability sector can enable the targeted enabling of data collection and trend mapping.

No organisation should be a single source advocacy provider. All advocacy services need to be required to engage in any service that meets the needs of the individual. Individual advocacy services that deal with one issue at a time or never aggregate issues and identify systemic themes are failing their constituents because they are failing to contribute valuable information to decision makers that lead to improvements in to policy and/or services. Systemic advocacy agencies that do not inform themselves of issues through active involvement in advocacy at an individual client level risk lacking the authority and integrity to speak on behalf of a constituency. Varied models of systemic advocacy will evolve through the influences of memberships and leaders. This is a healthy dynamic to encourage in the community sector.

It needs to be recognized that specific Peak bodies have over many years (in our organisation’s case; 35 years) developed a network of people with a disability, plus established relationships with a range of stakeholders and other government departments (i.e. Health, Housing, Justice), that would be at risk if Peak bodies were not funded in the future to provide systemic advocacy work. The wealth of knowledge attained by Peak bodies would be lost if consideration was not given to ensuring that these bodies continue to be funded for this overarching work.

The key aim of advocacy in general is promoting and protecting the rights of the individual with disability and empowering them to utilise their autonomy to have maximum choice and control over their own lives. In order to do this more focus should be placed on identifying the barriers that people with disability face in realising this goal and less on models that were arguably, primarily service, not client, centred in their establishment. This approach would then allow advocacy providers to develop eligibility criteria and approaches to advocacy that achieve outcomes as defined by the client group and move our society towards being fully inclusive of all members both individually and systemically.

We believe that systemic advocacy priorities need to be drawn from trends and common issues identified in individual advocacy work, at both a state and national level. The development of a shared online database or advocacy communities could assist to centralise this information and streamline the resulting systemic work. There is a need to acknowledge the expertise required in the varying areas of advocacy specialisation and to fund a program where NDAP contracts feature some flexibility to allow organisations to be responsive to need, whilst building partnerships to achieve common advocacy goals or referring to other organisations as appropriate to meet objectives.

In addition, ensuring that all NDAP funded advocacy bodies are involved in collaboration, information sharing and reporting issues, would allow for systemic issues and trends to be highlighted. This would enable opportunities for identified issues to be systemically addressed. It should be noted that most systemic issues would need to be managed by State based systemic advocacy organisations, whom have local understanding of laws and government policy that are applicable to the relevant State or Territory. Additionally some systemic issues that are specific to a particular type of disability may require a systemic agency that have expertise in working with that individual cohort.

Where an NDAP funded advocacy organisation chooses to also work as a service provider under the NDIS (for plan management and decision making supports) it would be important to ensure that the organisation has clear policies on managing conflict of interest. It should be noted that advocacy services have a deep knowledge of conflict of interest, as this is in fact what we manage in undertaking most of our advocacy work.

As individuals are provided with funding to gain access to ‘advocacy like activities’ within their funded packages, it would be not be fair to disallow NDAP advocacy organisations, especially those providing individual advocacy, to be registered as service providers. However there would need to be clear financial processes showing the division of funds spent on NDAP activities, as opposed to those provided through NDIS funding. In addition, it would be appropriate for these organisations to clearly show a policy/process for redress to another independent organisation or body (such as the Disability Ombudsman) should an NDIS client for whom they are advocating be unhappy with their advocacy provision.

We would suggest that numerous organisations in each State and Territory should be funded to support legal advocacy provision, and that this not just court based legal advocacy (which would by necessity need to be carried out by legal practitioners), but also advocacy organisations that support people through the whole legal process, such as police interviews and court ordered interventions.

Additionally, independent advocacy should be available for appealing decisions of the NDIS, where plans are inappropriately funded, i.e. through external merits reviews.

As is always the concern, the disparate nature of legislation between the states, particularly concerning the access to justice, is an area that can be addressed by using the NDAP program to target advocacy that assists people access justice.

Finally, if conflict situations arise, NDAP has already implemented independent review and audit processes that should continue to monitor agencies. We provide the following direct quotes from independent auditors that have reviewed our NDAP program to highlight the continued need for advocacy, in whatever form that best meets the individual’s needs and promotes their rights;

*´The Audit Team was impressed with the achievements of this small Advocacy*

*Team and the commitment of the Board, management and staff, without any form of discrimination, to promoting a positive vision for the lives and well-being of people with disability and advocating on their behalf.’*

Audit of Brain Injury Association of NSW Inc. Page 7 of 23

Against the Disability Advocacy Standards

Conducted by the Institute for Healthy Communities Australia Certification Pty Ltd Final

IHCAC 3627 Ver. 2.0 12-10-05 24 May 2013

*‘At the time of the Audit, BIA NSW was providing over 80 clients with Individual Advocacy (almost double the client base at the time of the 2013 audit). There were also considerable indicators of the organisation’s involvement in promoting Self Advocacy and also Systemic Advocacy projects, often in partnership with other government and community organisations. Several examples were noted and high praise received from senior government and other stakeholders contacted for ABI NSW’s contribution to major systemic issues impacting on people with brain injury, their families and carers, e.g. reforms to the NSW Civil and Administrative Tribunal and Electoral and Voting reforms (NSW Electoral Commission)*

*In general summary, the Audit Team remains impressed with the achievements of this small Advocacy Team and the commitment of the Board, management and staff, without any form of discrimination, to promoting a positive vision for the lives and well-being of people with disability and advocating on their behalf.*

*Maintenance of certification against the National Disability Advocacy Standards is recommended.’*

Audit of Brain Injury Association NSW Page 7 of 22 against the Disability Advocacy Standards Conducted by the Institute for Healthy Communities Australia Certification Pty Ltd Final IHCAC 3628. Ver.3.00 14-04-08 Date: 21-22 May 2014

*´Despite the difficulties with funding and the uncertainty and anxiety amongst staff, service delivery continues effectively with positive outcomes achieved for consumers. Consumers at interview were exceptionally positive in the comments on the services they have received. One consumer recommended the service be ‘gold plated’.’*

Audit of Brain Injury Association of NSW Inc. Page 6 of 17 against the National Standards for Disability Services Conducted by the Institute for Healthy Communities Australia Certification Pty Ltd Final IHCAC 3627 Ver. 4.00 15-01-06 Date: 18 May 2015

*´Clients appear to be well supported throughout their interaction with BIA NSW and are heavily involved in the development of Advocacy Plans. National Disability Advocacy Program funding is split 80% individual advocacy and 20% systemic advocacy, with individual advocacy by provided by an Advocate with a legal background. An extensive range of systemic advocacy matters has been undertaken by BIA NSW and the organisation is well networked across the state.*

*Human rights feature strongly in the BIA NSW ethos and it advocates for people with brain injury to live their lives as independently as possible. Privacy was well maintained and staff are committed to their advocacy roles. Staff and services provided by BIA NSW were held in high regard by the people interviewed as part of the Audit.’*

Audit of Brain Injury Association of New South Wales Incorporated, Page 5 of 20 against the National Standards for Disability Services Conducted by the Institute for Healthy Communities Australia Certification Pty Ltd Final IHCAC 3627 Ver. 7.00 16-01-27 30 May – 1 June 2016.

We believe these quotes from randomly selected advocacy clients demonstrate the continuation and strengthening of the NDAP funding.

**Michael Hampton**

**Community Voice Manager**

**Synapse (Brain Injury Association of NSW)**