National Disability Advocacy Program (NDAP) Review Discussion Paper Feedback

June 2016

Citizen Advocacy South Australia Incorporated (CASA) welcomes the opportunity to respond to the NDAP Discussion paper. Our response comes from over thirty years of study and experience in advocacy for people with disability.

**Introduction**

We support the objective of the NDAP which 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.’

To achieve this objective, disability advocacy must respond to the needs of people who are vulnerable with minimal conflict of interest and in the best interests of those people individually and collectively. For that reason we believe that the NDAP and the NDIS must remain totally separate. The Productivity Commission and people involved directly in disability advocacy have stated this in different ways over several years, yet this does not seem to be considered.

The Department of Social Services (DSS) recognises in the discussion paper ‘that outside of the NDIS (National Disability Insurance Scheme), people with disability will continue to require access to advocacy.’ Regardless of the ever changing landscape, the fundamental needs of vulnerable people have not and do not change, nor does their need to be protected, have their rights defended and voices heard. This means that advocacy which is ‘to plead in favour of; support or urge by argument; and advocates who ‘defend, vindicate, or espouse a cause by argument;’1 need not change if it is responding directly to the needs of those being advocated on behalf of.

There is no doubt that advocacy must be available to people who are vulnerable due to disability and associated factors. The study, “A Missing Piece: the need for independent advocacy in the NDIS quality and safeguarding framework” (Hannah Bill, Nov 2015) states that “this study identifies that without the provision of advocacy, the safety and well-being of vulnerable groups will be significantly impaired and the NDIS complaint systems will hold the potential to further disadvantage individuals in a system that increasingly places responsibility on the consumer.”

**The Vision for NDAP**

We are pleased that DSS is committed to a vision for NDAP, however there is an incoherency in the third point which is that ‘a reformed NDAP is one that …

* Integrates with and complements the services provided within the NDIS, by states and territories, and by mainstream organisations’

By definition advocacy stands apart from NDIS provided services and mainstream organisations to be the voice of those who are otherwise unheard. This does not mean being in conflict with NDIS provided services or mainstream organisations. It does mean managing conflict of interest by not being integrated with those entities.

Advocacy means being on the side of the disadvantaged party and having minimal conflict of interest. This third point compromises both of these fundamental principles of advocacy and in

1. Macquarie Encyclopaedic Dictionary 1990

doing so means it is no longer advocacy.

It would be more appropriate for the vision of NDAP to be ‘Provides accessible, timely, appropriate and independent advocacy support to people with disability irrespective of their age, disability type, cultural background, or place of residence *with minimal conflict of interest’*, without any reference to services provided by NDIS or mainstream organisations.

1. **Models of Advocacy**

Use of the word ‘model’ implies that there is a structured approach to the advocacy. It is more appropriate to talk about forms of advocacy not models of advocacy.

It is also imperative that ‘advocacy’ and ‘support’ are not confused but recognised as distinctly different activities. For example assisting someone with filling a form is not advocacy but is support. ‘Support’ can be service provided and paid for or freely given and unpaid.

1.1 **How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?**

Are we discussing advocacy or support in this question?

Presumably this question refers to forms of advocacy rather than forms of support.

The answer depends upon the forms of advocacy available. If the form of advocacy has broad and diverse application then it is likely to be more beneficial to the people requiring advocacy.

The focus in Citizen Advocacy enables programs to get better and better at providing quality advocacy in bringing together the right person with the protégé (person with disability).

Benefit comes from a consistent approach to people who are vulnerable by providing relationship based advocacy which has preventative, developmental and community building capacities.

People will benefit most when the form of advocacy is one that incorporates a broader perspective of vulnerability and needs of people than just their rights, through long term adaptable involvement and linking them to a range of flexible supports such as a network of people with expertise as they need.

For Example:

Legal advocacy can only provide legal support. It cannot provide the long term preventative support that would stop the person from returning to seeking advocacy over and over again.

**1.2 What are the drawbacks?**

A drawback of only having one or two forms of advocacy is that people’s options are

limited by the expertise available rather than getting what they need.

Rights only based advocacy is often limiting because it cannot take into account

vulnerability, readiness and maturity in decision making.

A major drawback of some forms of advocacy is that people may need to retell their

story, every time they seek advocacy, to people who do not know them. This is time consuming, frustrating, limited in relevance to the person’s real needs, inefficient, expensive and less likely to result in satisfactory outcomes.

Each form of advocacy has limitations and strengths therefore a full range of disability advocacy forms must be available to avoid drawbacks as much as possible.

**1.3 How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?**

People should have access to a wide range of advocacy options including those which focus on seeking out vulnerable people (rather than relying on referrals) and build long term relationships of support (Citizen Advocacy) to ensure a greater chance of accessing the option that best suits that person and their circumstance.

Funding and auditing on an annual basis is highly problematic in long term strategic planning for advocacy organisations. The resources of most disability advocacy organisations are very limited and can easily be disrupted by funding uncertainties. Even now, the established knowledge base and expertise in disability advocacy is at risk by current reviews and increasing bureaucracy.

To ensure that advocacy meets the expectations of all the stakeholders it needs to be valued and adequately funded to increase the various forms of advocacy to enable growth and forward planning in the sector. This means that new funding is required to seed new programs and better support the development of existing programs.

1. **Improving access to advocacy supports**

**2.1** How do we improve access for:

* + people with disability from **Aboriginal and Torres Strait Islander communities** and their families;

* + How do we improve access for people with disability from **culturally and linguistically diverse communities** and their families?
  + How do we improve access for people with disability in **rural, regional and remote** locations?
  + How do we improve access for people who are **very socially isolated including those with communication difficulties and those in institutional care**?

Every NDAP funded program should have in entry policies with no barriers to any of these groups and should reflect inclusion in policies and practices.

Where isolated groups are identified due to location funding should be made available to support a diverse range of advocacy in these areas.

Recognition of the specific needs of people experiencing social isolation, communication issues and institutionalisation must be made by ensuring that forms of advocacy that have experience in these areas are readily available.

**2.2 What are the strategies or models that have worked? What are the strategies that do not work?**

Advocacy at a distance does not work. Proximity to the people who are vulnerable is the first ingredient to success in disability advocacy. It all works best when advocacy support is available locally.

Getting the best fit between the advocate and person requiring support is another important ingredient.

Coherent, consistent, intentional relationship based advocacy works because it is not dependent upon payment of the advocate, minimises conflict of interest, is sustainable over the long term, has preventative and developmental safeguards and provides a broad range of support.

It also works well to seek out vulnerable people who would otherwise never seek out or not be able to contact an advocacy agency. It works well if you really know and understand the person for whom you are advocating.

What works less well is fragmented and inconsistent support on ad hoc and reactive basis.

It doesn’t work well to have a number of forms of advocacy working out of one organisation.

Several different advocates from various agencies involved with one person is very ineffective.

It absolutely does not work when the advocacy is provided as a part of service provision paid by the same service due to the degree of conflict of interest. In these situations it is impossible to safeguard the advocacy.

When an advocacy agency is doing non-advocacy activities, even with fire walling, it cannot protect the organisation from conflicts of interest.

**3. Improving the advocacy evidence base and coordination on systemic issues**

**3.1 What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?**

Systemic advocacy needs to be funded separately from independent advocacy.

Systemic advocacy agencies are responsible for gathering the information from a broad field, that may or may not include NDAP funded organisations, and targeting or sharing that information with the appropriate people and organisations to get action. NDAP should not have control over this process.

**3.2 How can we help disability advocacy organisations work with a wide range of other organisations with similar aims such as:**

**. disabled people’s organisations (DPOs)**

**. the Australian Human Rights Commission**

**. Ombudsman organisations**

**. aged care advocacy organisations**

**. state disability advocacy organisations**

**. peak bodies?**

It is not the role of NDAP funded advocacy organisations to help other organisations to their job, ie collecting their data. Each of the organisations listed here is responsible for collecting their own data. In fact, it is the responsibility of these organisations (apart from aged care and state funded disability advocacy) to support NDAP organisations.

Advocates may choose to contact any of these organisations themselves as the need arises.

NDAP funded advocacy organisations do not have the resources and staffing to do this work which could become a major distraction to the core work of the advocacy organisations hence reducing their efficiency and potency.

1. **The interface with the NDIS and addressing conflict of interest**

**4.1 What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?**

First and foremost NDIS providers should not provide advocacy in any form. Advocacy organisations should not be providing any services other than advocacy. This is the only way of ensuring that conflict of interest issues do not arise or are minimised and that people are treated fairly.

For example, an organization that provides a range of services including accommodation, employment support and day activity programs cannot then claim to provide independent advocacy. This is especially true if the ‘independent advocate’ is contracted by the organisation. A person having difficulty with any aspect of services provided by the organisation cannot then be guaranteed that the ‘independent advocate’ is on their side and not on the side of protecting the organisation’s reputation, staff or board.

**4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP**

There should be a clear gap (differentiation) between NDIS and NDAP because they are completely different in focus and in purpose. NDAP should (because it is advocacy) be highlighting issues in the NDIS which require the NDIS to respond. It is not appropriate for the NDIS to determine the focus and purpose of the NDAP (which is on the side of the disadvantaged party and has minimal conflict of interest).

For example if a person is seeking to leave a service organisation and seeks advocacy to do so, if that advocacy is provided by another service organisation, the advocate will be obliged to recruit that person into their service regardless of what is in the best interest of the person.

This is supported by the Productivity Commission’s 2011 recommendation that “advocacy should not be funded under the NDIS due to conflict of interest and instead should remain under a block funding model”.

**4.3 What policies and strategies do we need to protect the rights of people with disability?**

There should be a range of real advocacy options available to people with disability. By real advocacy options we mean being on the side of the disadvantaged party and having minimal conflict of interest. This means that advocacy cannot be provided or subcontracted by service providers. Advocacy must be independent.

1. **Understanding and improving access to justice**

Legal representation is not done by advocates but by lawyers, barristers and solicitors even though they may refer to themselves as advocates.

**5.1 What forms of legal review and representation do people with disability need most?**

Please refer to the National Disability Justice Plan Symposium which addresses the issues raised by these questions.

Legal representation for people with disability should be based in well-resourced legal services commissions and community legal services.

**5.2 What barriers prevent people with disability from accessing justice?**

Most people with disability consider agents of the justice system to be there to punish them rather than to support them.

Too many people have so few people in their lives to recognise when a crime is being committed against them and too many issues are being dealt with ‘in house’ instead of transparently. This is another reason why service providers should not be involved in advocacy.

Some people live in isolation and are assumed to have chosen this lifestyle. These people are often assumed not to need advocacy because of their lifestyle.

Legal language, culture and environments are intimidating and confusing therefore making communication even more difficult for the person with disability. Legal processes don’t recognise the diversity of communication styles required to communicate well with people who have disability.

The legal system assumes the perpetrator isn’t in fact a victim and fails to recognise the person’s history, disability, communication styles and issues. There is a lack of recognition and referral of people who are having difficulties and may in fact be victims of serious crimes eg a person going to the police to report being raped several times should serve as ‘alarm bells’ for the police to refer that person to somebody who can help, eg an advocacy agency instead of dismissing the person’s experience as inconsequential.

A person who is a victim and then becomes the perpetrator has never had support or acknowledgement.

* 1. **What models of legal advocacy are most effective?**

Like interpreters for people who cannot speak English, advocates who know and understand the person well can be the spokesperson or interpreter for the person with disability to ensure most effective representation. The advocates cannot be the legal representatives because legal representation must come from legal professionals (via well -resourced legal aid and community legal services) working together with the advocate and person with disability.

Representation currently depends on your bank account and status in the community.

“It’s better for you to be rich and guilty than innocent and poor” (Bryan Stevenson)

**Additional Comments**

The discussion paper seems to be confused as to the relationship between the NDAP and the NDIS.

There appears to be confusion or lack of understanding of what advocacy is and the wording of this discussion paper is very poor and misleading.

All advocacy connected to service providers is totally inappropriate. There are differences between internal grievance and complaints processes and advocacy.

The service providers are the businesses and the people the commodities. Advocacy redefines the commodities as people through ensuring that the focus is on people as people.

There may be value in disability advocacy organisations having a peak body representing them and their contribution to communities locally and nationally. DANA has to date filled that role but has been poorly resourced to do this as well as could be. It is important that any peak advocacy organisation has a solid understanding of social advocacy and its relationship to ever changing Government policies.

**Summary**

Every person with disability has a right to safety, justice and opportunities under the UNCRPD.

NDAP funding has incorporated into it an adherence of these rights for people.

Advocacy should not be paid for by the person within NDIS package, however NDAP funding needs to be substantially increased and not attached to NDIS in any way to align itself with UNCRPD.

Advocacy needs to be available to any person at any time as needed and provided by agencies focussing solely on advocacy.

Our final contribution to the discussion paper is to draw attention to a range of recent documents which highlight the value of advocacy in some form:

* Productivity Commission, 2011
* Is the Government removing independent advocacy by stealth? (DANA Andrea Simmons, 2013)
* Speaking Up: A Cost Analysis of the Unpaid Work of Citizen Advocates (Felicity Brooks, 2015)
* National Disability Advocacy Framework Feedback (Citizen Advocacy SA July 2015)
* A Missing Piece: the need for independent advocacy in the NDIS Quality and Safeguarding Framework (DANA Hannah Bill, Nov 2015)
* Submissions published on advocacy and support and therapeutic treatment services (Royal Commission into Institutional Responses to Child Sexual Abuse, May 2016)