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ADACAS submission

national disability advocacy program review

**INTRODUCTION**

ACT Disability, Aged and Carer Advocacy Service (ADACAS) welcomes the opportunity to make a submission to the review of the National Disability Advocacy Program (NDAP). ADACAS is celebrating its 25th anniversary as an independent advocacy organisation and provides advocacy to people with disability, frail older people and their carers in the ACT and region. Our vision is “a world in which everyone may exercise their rights and responsibilities, lead lives of value and dignity and pursue their dreams.” Our mission is to “assert, promote and protect the rights and potential of people with disabilities, people who are older and people who are caregivers.”

ADACAS is a current recipient of NDAP funding for individual advocacy with a small component of systemic advocacy. We also receive funding from the Commonwealth for older persons advocacy and through the ACT government for mental health and disability advocacy. ADACAS also provides the support person for External Merits Review of NDIS decisions and undertakes a range of projects including supported decision making. We have a Board of volunteer Directors and a strong reputation for providing high quality independent advocacy in Canberra. ADACAS maintains full certification against the National Standards Disability Services (previously the national disability advocacy standards) and has never received a qualified audit report.

The NDAP Review discussion paper canvasses a range of issues which many other submissions have addressed. ADACAS endorses the recommendations made by the Disability Advocacy Network Australia (DANA) submission to the review.

Rather than duplicate effort taking place elsewhere, ADACAS has chosen to focus our submission on the issue of independence of advocacy, conflict of interest and the impact of changing landscape on the advocacy sector. This decision does not indicate that ADACAS does not have a view on other matters, rather it reflects the time constraints under which we all work.

ADACAS would welcome the opportunity to take part in forthcoming aspects of the NDAP review, including focus or working groups on these topics.

**RECOMMENDATIONS**

1 That for the purposes of NDAP, independent advocacy means speaking, acting or writing in support of or on behalf of a person or group with minimised conflict of interest. An independent advocacy organisation is:

* An organisation that has been established as a discrete entity (under relevant state or national laws) with the purpose of providing disability advocacy within a human rights framework to people with disability and maintains its structural independence
* An organisation that is as free from conflicts of interest as possible through:
  + Managing its relationships with other stakeholders
    - Service providers – so that the advocacy provided can represent solely the interests of the person with disabilities
    - Funding bodies – so that political or other factors do not interfere with the advocacy provided for individuals
    - Family members and friends – so that the interests, wishes and needs of the person with disability guide the advocacy
  + Ensuring that it represents each person with disabilities according to their wishes
  + Providing systemic advocacy that is informed by the individual advocacy it provides (or is provided by allies) or informed by the wisdom and experience of people with disability themselves.
  + Putting in place policies and procedures that protect the independence of the advocacy it provides, including managing conflicts of interest for the organisation, individual staff members, individual board members and individual advocacy cases.
  + Operating with a culture of reflective practice that enables it to recognize and act to minimise conflict of interest issues
* An organisation that seeks to ensure that all activities of the organisation are undertaken consistent with its purpose of advocating for and with people with disabilities so that they are valued and included members of the community.

2 That independent advocacy organisations funded under NDAP may undertake other activities that are undertaken within an advocacy framework. That a mechanism to monitor the quality of the service (such as a code of conduct), particularly its consistency with advocacy principles, be put in place through DANA, in addition to existing quality audit requirements for NDAP.

3 That funded organisations may deliver independent advocacy and other activities that share the following principles and practices:

* Provided within a human rights framework
* Guided by the needs and wishes of the person with disability
* Speaking with the voice of the participant not the advocate/paid person
* Delivered by an organisation that does not have a conflict of interest through providing other traditional disability services
* Delivered without conflict of interest with funding bodies (noting that in the NDIS context it is the person who is purchasing the activity), disability service providers or family members.
* Intentional empowerment of the individual through building capacity and skill
* Able to advocate effectively for the person, with disability service providers and other service systems and domains (such as education, health, housing, justice…)
* Never acting in a way that increases a person’s marginalisation and devaluation, or leaves them more vulnerable to the consequences of marginalisation and devaluation.
* Safeguarding particularly isolated or vulnerable participants.

4 That a range of options for access to advocacy are available to people with disability including:

* Block funded advocacy on any issue
* A range of different models of advocacy
* Choice of advocacy organisation
* Advocacy like services that people can choose to purchase

5 That DANA be funded to support the advocacy sector to explore a range of different ways of providing advocacy and evaluate their appropriateness and effectiveness, including:

* Delivery of advocacy through different funding models
* The viability and effectiveness of other models of volunteer advocacy (in addition to citizen advocacy)
* Use of technology to improve access to advocacy for remote and regional centres

6 That significant additional funding be provided for independent advocacy, while enabling advocacy-like activities to be delivered by independent advocacy organisations as part of a consumer directed market (with appropriate safeguards) to increase the availability and diversity of advocacy models available to people with disability.

**INDEPENDENCE**

An underlying principle of disability advocacy has always been the question of independence to ensure that the person’s voice is what is directing and what is heard throughout the advocacy work.

ADACAS recognises that much has been, and will continue to change in the nature of supports for people with disability. Advocacy organisations have been strong champions for the need for change. ADACAS recognises that:

* advocacy is not, and nor should it be, immune to change
* new ‘advocacy-like’ roles are being introduced through the NDIS, the Information, Linkages and Capacity Building (ILC) sector and the quality and safeguarding sectors
* governments are reviewing the advocacy sector and their expectations and understanding of the place of advocacy in the new environment
* existing advocacy models have served people with disability well over many years and continue to be valuable
* each existing advocacy organisation will respond to environmental change differently.
* The broader context of not-for-profit sector reform is leading to a reduction in the number of NFP organisations and the policy environment is such that it will be increasingly difficult for small organisations to survive.
* The nature of the NFP sector relationship with government introduces a tension whereby government may seek to direct what organisations may do through funding contracts.

One of the key strengths of the independent advocacy sector is its diversity. Organisations vary in size, location, model and specialisation which ensures that people needing advocacy have real choice of the advocacy that best meets their needs. Any move to introduce greater consistency into the advocacy sector needs to be balanced with the need to ensure that a ‘one-size-fits-all’ approach is not adopted. Indeed the consistency that is required is ensuring that across the country people with disability have consistency of choice –that is they can all access a range of different advocacy services depending on their needs.

Historically the National Disability Advocacy Framework and the National Disability Advocacy Program have expressed a preference for disability advocacy to be provided by organisations that do not also deliver other services although a number of currently NDAP funded organisations do also deliver other services. While the revised NDAF has not been released it is unlikely that it will be more restrictive than the existing framework.

The argument about independence essentially relates to conflict of interest. Historically it has been simplest to manage conflict of interest by simply avoiding it however, in our current environment a more sophisticated approach to conflict of interest is required.

Some advocacy organisations maintain a very narrow interpretation of the importance of independence of advocacy and consider only “pure” advocacy organisations to legitimately belong to the sector, indeed some believe that a conflict is introduced if more than one model of advocacy is delivered by the same organisation.

Such a view introduces very real viability risks and has seen the closure of some organisations. Many advocacy organisations therefore do actually already undertake other project work which is related to advocacy. It is therefore clearly not appropriate to define independence for the purpose of the NDAP model, so narrowly that these ancillary activities are not able to occur.

Other advocacy organisations have objected to the restriction and argue that particular activities do not constitute a “service” in the traditional sense, or that the organisation has sound governance and documented policy and practice to deal with any potential conflict.

In the current political environment independent disability advocacy and independent advocacy agencies are under pressure. In most states and territories funding for advocacy has remained static or declined over the last several years. NDAP funding has remained static and indexation has not kept pace with CPI or general inflation, resulting in a de facto reduction in funding. Many advocacy agencies are considering ways to access additional funding from non-advocacy specific sources to ensure organisational viability. This includes mergers, partnering with advocacy or non-advocacy agencies, or undertaking non-advocacy specific activities. NDIS is, of course, one of the funding sources being considered. It has previously been suggested that self-advocacy, assertiveness training, supported decision making and support to self-advocate could be a funded support under the NDIS. Attracting additional funding may be critical for organisational viability.

In addition many advocacy agencies are also increasingly interested in undertaking training, capacity building, and other activities that might not strictly be considered traditional advocacy activities. Agencies representing particularly disadvantaged population groups have undertaken such activities and in some cases more traditional service provision for some time (e.g. some Brain Injury organisations). Organisations may be approached with a funding offer or such activity may reflect lack of service for the particular population group or region.

In other words increasing numbers of advocacy agencies are likely to be undertaking activities other than strict provision of independent advocacy and information.

Defining “independent advocacy” and “service provision”?

How to define the concept of “independence” in independent advocacy and the types of activities that are and are not regarded as “service provision” is critical to this discussion.

Advocacy provided by a provider of traditional disability support services clearly introduces a risk of conflict of interest and ideally should not occur. However, a substantial grey area exists between that and organisations that only provide block funded advocacy and information.

Independence and conflict of interest

“Independent advocacy” is not currently well defined. Dictionary definitions of ‘independent’ use phrases like:

Independent – *self governing; free from outside control; not subject to another’s authority; not depending on another for livelihood or subsistence; not influenced or controlled by others in matters of opinion, conduct, etc.*

It is not possible to be completely without the influence of others. Disability advocates are (in many cases) employed and paid to act as advocates, which gives them a personal interest in the relationship between themselves, the consumer and their employing organisation. Disability advocates form relationships with their advocacy clients. Disability advocates often encounter the same officials, public servants, and service provider representatives repeatedly in their advocacy practice, as well as in other forums, and may form professional relationships with them which assist the achievement of outcomes for individuals. Advocates have private relationships with people who, in particular in small communities, may have relationships with the service providers and government agencies the advocate encounters in their advocacy practice. Advocates manage these relationships and avoid conflicts of interest by employing good professional practice. Government funding brings conflicts of interest to the advocacy sector. Families and individuals also have conflicts of their own. Advocacy agencies manage these potential conflicts of interest through implementing policies to identify, manage and resolve conflicts of interest. In other words “independent” does not necessarily mean a complete absence of conflicts of interest, but rather being aware of potential conflicts of interest and being vigilant in minimising and managing such conflicts.

Independent advocacy means speaking, acting or writing in support of or on behalf of a person or group with minimised conflict of interest. An independent advocacy organisation therefore is:

* An organisation that has been established as a discrete entity (under relevant state or national laws) with the purpose of providing disability advocacy within a human rights framework to people with disability and maintains its structural independence
* An organisation that is as free from conflicts of interest as possible through:
  + Managing its relationships with other stakeholders
    - Service providers – so that the advocacy provided can represent solely the interests of the person with disabilities
    - Funding bodies – so that political or other factors do not interfere with the advocacy provided for individuals
    - Family members and friends – so that the interests, wishes and needs of the person with disability guide the advocacy
  + Ensuring that it represents each person with disabilities according to their wishes
  + Providing systemic advocacy that is informed by the individual advocacy it provides (or is provided by allies) or informed by the wisdom and experience of people with disability themselves.
  + Putting in place policies and procedures that protect the independence of the advocacy it provides, including managing conflicts of interest for the organisation, individual staff members, individual board members and individual advocacy cases.
  + Operating with a culture of reflective practice that enables it to recognize and act to minimise conflict of interest issues
* An organisation that seeks to ensure that all activities of the organisation are undertaken consistent with its purpose of advocating for and with people with disabilities so that they are valued and included members of the community, their fundamental needs are met and their human rights are respected.

Activities compatible with advocacy

It is possible to describe and give examples of the types of activities, which are compatible with advocacy or – in other words – services that are not considered traditional disability service provision. These could include:

* An activity which aims to build capacity in participants for awareness of rights including on the issues of discrimination, stigma, stereotyping, human rights, social exclusion, inclusive communities, advocacy and self-advocacy. This may include:
  + Community education and training for people with disabilities, their families and supporters
  + Capacity-building programs, including buddy-programs, peer support and self-help groups, and tailored social groups
  + Decision making support based on advocacy principles
  + NDIS preparation and advice on individual funding packages
* An activity which aims to provide participants with information about a particular disability, its effects and impacts for the individual, and how to respond sensitively to these impacts. This may include:
  + Community education and disability awareness training for the general community
  + Tailored disability awareness training for service providers and professional groups
  + Provision of disability specific resources material
* Being a representative Disabled Persons’ Organisation
* Managing scholarships or specific-purpose small grants programs
* Providing free and independent information and referral services particularly where the provision of information and referral has consideration also for the quality of the service referral being made.

Where an independent advocacy organisation is undertaking additional activities such as those described above, there would appear to be little risk to their independence.

Activities not compatible with advocacy

Traditional disability service provision is not compatible with independent advocacy. These activities include:

* accommodation support, supported employment, provision of day programs, traditional case management, sale of disability aids or equipment, transport, or provision of physical care services.
* Training outside of the area of advocacy and the rights of people with disabilities, e.g. OHS, disability services.

Activities that may be compatible with advocacy

The Council of Australian Governments' (COAG) Disability Reform Council decided in April 2015 that systemic advocacy, legal review and representation would be funded outside the NDIS and that the NDIS would fund:

* decision supports
* safeguard supports
* capacity building for participants, including support to approach and interact with disability supports and access mainstream services.

While the COAG decision does not specifically mention individual advocacy and how it should best be funded, the decision identifies some components of independent advocacy as being appropriately included in NDIS packages and/or the ILC sector.

There are a range of activities therefore that may, depending upon the manner in which they are delivered, be compatible with independent advocacy. These include linking services, some models of local area coordination, support coordination or support with self-management of individual funding packages.

These activities may be funded through block funding directly from governments; philanthropy or fundraising; or directly by an NDIS participant who is exercising choice and control in the market to select an organisation to provide an advocacy model of service within an individualised funding package.

Activities of this type should only be considered acceptable if they are undertaken within an advocacy framework. Ideally a mechanism to measure the quality of the service, particularly its consistency with advocacy principles would be in place through DANA. Existing quality audit requirements for NDAP are essential for this purpose, in addition adopting an Advocacy Code of Conduct or formal Advocacy Principles may enable this to occur.

In some circumstances, undertaking other activities within an advocacy framework may lead to better outcomes for the individual than can be achieved through current independent advocacy models alone.

* It may enable the advocacy organisation to act as a safeguard for particularly vulnerable individuals through remaining engaged even when an advocacy issue is not present, this may prevent or minimise future crises.
* It may enable increased social connection (such as through participation in group activities)
* It may provide additional opportunities to influence the actions of others (such as through providing training to disability service providers).

Conversely, it will be important for organisations to be alert to situations where provision of other activities, within an advocacy framework, is no substitute for independent advocacy and ensure that where this will lead to the best outcomes for a person, it is only independent advocacy that is provided.

For the purposes of independence in relation to NDAP, a useful distinction is that funded organisations may deliver independent advocacy and other activities that share the following principles and practices:

* Provided within a human rights framework
* Guided by the needs and wishes of the person with disability
* Speaking with the voice of the participant not the advocate/paid person
* Delivered by an organisation that does not have a conflict of interest through providing other traditional disability services
* Delivered without conflict of interest with funding bodies (noting that in the NDIS context it is the person who is purchasing the activity), disability service providers or family members.
* Intentional empowerment of the individual through building capacity and skill
* Able to advocate effectively for the person, with disability service providers and other service systems and domains (such as education, health, housing, justice…)
* Never acting in a way that increases a person’s marginalisation and devaluation, or leaves them more vulnerable to the consequences of marginalisation and devaluation.
* Safeguarding particularly isolated or vulnerable participants

Organisations can manage potential or perceived conflict of interest when delivering other activities in an advocacy model by:

* Structural separation within the organisation
* Being partisan on the side of the person with disability
* Actively engaging with the person to build their capacity and independence
* Using supported decision making frameworks to ensure that activities are guided by the participant
* Clear articulation that funding decisions rest with the individual NDIS participant not the agency
* Policies that guide decisions about whether providing an alternative activity, such as support coordination by the advocacy organisation is going to lead to the best outcome for the participant (particularly where they may also need other advocacy)
* Sound organisational policies and reflective practice
* Sound complaints management processes (including how complaints that need advocacy will be managed)
* Ensuring that an advocacy based organisational culture is maintained across all teams within the organisation.

The Public Advocate Queensland submission to this inquiry correctly notes that independent advocacy needs to be free of both actual and perceived conflicts of interest. It goes on to express concern about the strong influence that organisational culture has on the work of advocates and the importance of ensuring that advocates do not become captured by an organisational culture of traditional service delivery. Independent advocacy organisations that develop new models of advocacy, including delivery of NDIS line items within an advocacy model, will need to remain alert to ensure that the organisational culture remains one of advocacy and independence. Such a task is achievable however, and a useful distinction remains between service providers who seek to also provide advocacy, and advocacy organisations that seek to continue to provide advocacy but in new ways consistent with the changing landscape of the sector.

Managing complaints

A key area of concern about conflict of interest is the managing of complaints. There is recognition that people with disability may need the support of an advocate in order to make a complaint about a service that they are not satisfied with, including a service that is delivered by an advocacy organisation. This is indeed true. However, clients of advocacy organisations are already entitled to make a complaint about the advocacy service that they receive from independent advocacy organisations. Advocacy organisations are already required to have accessible complaints processes in place for advocacy clients to access. If they are delivering other advocacy-like activities the existing complaints mechanisms should be available to all clients. Clients of any new activity must be made aware of their right to complain and be supported to do so in the same way as for block funded advocacy. Given that clients already access complaints about advocacy services with or without an advocate, there should be no need for change to complaints processes where advocacy organisations are truly delivering advocacy-like activities in a manner that is fully consistent with the values and principles of independent advocacy.

Conflict of interest and funding mechanisms

If well run, values based advocacy organisations are able to design, deliver and sustain activities that are delivered within an advocacy model as described above, without introducing conflicts of interest that compromise the quality of advocacy for individuals. The result may be an increase in the amount of advocacy available to people with disability. This would be a good outcome.

Possible funding mechanisms for advocacy include:

* block funding arrangements between governments and advocacy organisations. Clients access a ‘free’ service and are unaware of the cost basis on which that service is provided;
* advocacy provided through charitable donations which would involve the advocacy organisation competing for funding from foundations or philanthropics or fundraising directly from the public;
* advocacy like activities funded through ILC, such as self advocacy support;
* advocacy like activities funded through individual packages;
* advocacy paid for by the client.

Each of these mechanisms introduce the potential for different conflicts of interest.

Table 1 shows that the funding source has the potential to impact upon the nature of the relationship between advocacy organisation and the client. This could be either a positive impact (empowering for client); neutral; or a negative impact (nature of advocacy impacted by funding source).

Table 1

|  |  |  |
| --- | --- | --- |
| *Funding source* | *Nature of relationship* | *Conflict - potential* |
| Government Grant | Conflict exists where government is also a service provider or also a party to the advocacy issue.  Manage relationship with government funders.  Uncertainty of funding.  Client unaware of funding source. | Government does not welcome advocacy that identifies gaps or inappropriate policy/practice.  Government influence over systemic advocacy.  In most cases actual conflict unlikely. |
| Fundraising | Organisation accountable for expenditure of donations puts pressure on delivering outputs which may impact quality/duration of advocacy.  Uncertainty of funding.  Client or family potentially asked for donations. | Source of donation may introduce a conflict.  Organisation may cherry-pick clients that are good for PR so they can raise more funding.  Organisation need for PR may influence nature of advocacy provided. |
| ILC | Manage funding relationship with NDIA.  Client not necessarily aware of funding source. | NDIA funds the ILC so may be perception that it could influence advocacy delivered.  Actual conflict unlikely. |
| Individual package | Organisation now accounts to the individual for the time spent on advocacy and the outcomes achieved.  Potential to empower the individual to have more control over the advocacy they receive.  Client able to track expenditure. | Perception that organisation will seek to ‘capture’ the client in some way because they need the revenue. Can be managed through values of organisation.  NDIA may influence nature of advocacy by reducing funding in subsequent plans. |
| Fee for service | Private transactional relationship similar to any other business that provides a service/information/ advice such as lawyer, financial advisor.  (Private advocacy organisation for older currently people exists in Victoria). | Nature of relationship is one of customer : provider. Same expectations as for other customer relationships. |

While not currently widely understood, funding decisions made by governments already affect the nature of the funding relationship between organisations and clients – clients are only able to freely access advocacy that the government has chosen to fund – through limiting the choice that the client has over advocacy models, number of advocacy organisations in a given location and amount of advocacy available. Block funding of advocacy therefore has the impact of limiting individual choice. The Office of the Public Advocate Victoria in its submission to this review notes that:

“Block funding of advocacy services is contrary to the market philosophy of the NDIS. Once the NDIS model is in operation, people with disability will be able to receive funding in their plans to purchase advocacy services.”

Advocacy provided through individual packages has the benefit of providing greater choice and control to the individual. They could choose for instance:

* To fund an advocacy service to find them a citizen advocate which would achieve a goal of increasing safeguards for a vulnerable person, increasing connection to community for an isolated person or capacity building
* To build capacity through participation in a self-advocacy group
* To access plan management provided by an independent advocacy organisation because the client values the additional independence and scrutiny that this offers them
* To access support coordination delivered in an advocacy model because they realise they need additional assistance to speak up to service providers and others to enable them to achieve their goals, because they value the independence from any service provider (and the conflict of interest that introduces) because they know the advocacy organisation will work on their expressed wish, because this introduces an additional safeguard for a vulnerable person.

In essence, advocacy organisations delivering activities through more individualised funding will introduce greater diversity into the market – a key outcome the NDIS is seeking. Increased diversity in the market leads to good outcomes for individuals because they can exercise informed consumer rights which will improve service quality and outcomes for individuals.

Ideally the needs and wishes of people with disability would be best served by ensuring that they have a range of options to access advocacy:

* Block funded advocacy on any issue
* A range of different models of advocacy
* Choice of advocacy organisation
* Advocacy like services that they can choose to purchase

Clearly while advocacy on issues related to the NDIS will be increasingly important for those who are eligible for the NDIS, demand for advocacy on other issues will remain and advocacy will also still need to be available to those who are not eligible for the NDIS.

While the existing funded advocacy models have served the community well over many years, the advocacy sector needs to be open to new ideas, new opportunities and change to meet the changing needs of people with disability and the changing landscape in which they live. The advocacy sector could explore a range of different ways of providing advocacy and evaluate their appropriateness and effectiveness, including:

* Delivery of advocacy through different funding models as discussed above
* The viability and effectiveness of other models of volunteer advocacy (in addition to citizen advocacy)
* Use of technology to improve access to advocacy for remote and regional centres

Sustainable funding for DANA would be an essential prerequisite to undertaking trials of new models of advocacy. As the peak, DANA is in an ideal position to recruit and support advocacy organisations with an interest and capacity to undertake trials and report on outcomes achieved. Such activity fits appropriately within the role of a sector peak and can also inform other activities such as professional development and support to maintain quality and assurance standards.

NDAP review and independence

The NDAP review discussion paper poses questions about mechanisms to ensure that a range of advocacy models are available to people throughout Australia. The stated vision for a reformed NDAP (page 3) would only be achievable with the injection of significantly more funding for advocacy than that which has been available (through NDAP and state funding) to date. Enabling advocacy-like activities to be delivered as part of a consumer directed market (with appropriate safeguards as discussed above) would go some way towards increasing the availability and diversity of advocacy models available to people with disability.

Where an independent advocacy organisation is providing advocacy like activities in a manner that is compatible with independent advocacy there should be no impediments to the organisation also receiving NDAP funding to provide independent advocacy. NDAP could determine this through:

* Understanding the purpose of the organisation – was the organisation established to provide independent advocacy or for another purpose?
* Articulation of the model that underpins the delivery of all activities undertaken by the organisation – is the model based in advocacy principles and human rights
* Clarity of separation of activities to ensure no cross-funding is occurring
* Management of conflict of interest and complaints through policy and procedures
* Compliance with standards, codes of practice or DANA membership

**CONCLUSION**

Continued commitment to the National Disability Advocacy Program by the Commonwealth government is a very welcome recognition of the important role that independent advocacy will continue to play in the lives of people with disability.

While it continues to be imperative that independent advocacy is sufficiently funded through block funding to ensure that any person with disability can access independent advocacy when they need it, the NDIA represents an opportunity for people to also access advocacy through different funding mechanisms, including ILC and individual packages.

Delivery of advocacy like activities does not put at risk the independence of NDAP funded advocacy as long as the organisation is established and managed appropriately through having structures, policies and practice in place to manage and minimise conflict of interest and continue to work in accordance with advocacy principles. The NDIS provides an opportunity for individual participants to have greater choice and control not only over the design and delivery of their disability services, but also over the nature and quality of the advocacy that they receive.