

# **Review of the National Disability Advocacy Program**

## **Consultation Report**

**July 2017**

## Contents

1.	Executive summary .....	3
2.	Purpose of the report.....	5
3.	Key themes .....	6
4.	Sources of information.....	8
	DSS engage website .....	8
	Meetings with stakeholders .....	8
	Focused workshops.....	8
	Review of the National Disability Advocacy Framework (NDAF).....	9
	Information from consultations by Joint Standing Committee into the NDIS.....	9
	Senate Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings .....	9
	NDIS Quality and Safeguarding Framework .....	10
	Research of the models of advocacy funded under NDAP .....	10
5.	Defining advocacy and its interface with other supports .....	12
	Table 1: Purpose, independence and focus of NDAP advocates versus other support roles .....	14
6.	Summary of findings.....	16
	Models of advocacy.....	16
	Improving access to advocacy supports .....	18
	Improving the advocacy evidence base and coordination on systemic issues .....	22
	The interface with the NDIS and addressing conflict of interest .....	23
	Understanding and improving access to justice .....	25
7.	References.....	28

## 1. Executive summary

People with disability and their families often experience severe social, financial and personal disadvantage over their whole lives.

Advocacy services seek to support people with disability to exercise their rights and freedoms through: the provision of individual advocacy support; supporting people to advocate for themselves; and/or influencing long-term, systemic changes to ensure that rights and freedoms are attained and upheld.

Responsibility for funding disability advocacy in Australia is currently shared between the Commonwealth and state and territory governments, with the exception of South Australia. There are also a small number of advocacy organisations that are not funded by government.

The Commonwealth Government funds approximately half of all disability advocacy services across Australia through the National Disability Advocacy Program (NDAP). The objective of 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.

In 2016-17, fifty-eight advocacy agencies in locations across Australia were funded in the vicinity of \$17.7 million under the NDAP. Approximately 12,000 people with disability are expected to receive individual support, and a broader group of people with disability will benefit through information and referrals and from agency support in progressing systemic matters on their behalf.

### NDAP review

The Department of Social Services (DSS) is currently reviewing NDAP. As noted in the Review of the NDAP Discussion Paper (DSS engage website, 2016) (the Discussion Paper), although there have been some minor reforms and improvements made to NDAP since its establishment in the 1980s, it has been a challenge for funding and policy to keep pace with the cultural and demographic changes. Further changes are expected with the roll-out of the National Disability Insurance Scheme (NDIS).

The NDAP reform process is aiming to make improvements in a number of areas including:

- geographic availability of advocacy support
- access for Aboriginal and Torres Strait Islander (ATSI) communities and Culturally and Linguistically Diverse (CALD) communities
- access for people with disability in rural, regional and remote locations, as well as people who are very socially isolated
- data collection
- coordination of systemic issues
- the interface with the NDIS
- access to justice.

The DSS vision for a reformed NDAP is one that:

- provides accessible, timely, appropriate and independent advocacy support to people with disability irrespective of their age, disability type, cultural background, or place of residence
- includes a data collection system that contributes to the evidence base and provides information on systemic issues to policy makers
- integrates with and complements the services provided within the NDIS, by states and territories, and by mainstream organisations
- includes a consistent and equitable funding model.

### Consultation

Throughout the consultation process, feedback has been received from a wide range of stakeholders including people with disability, carers and family members of people with disability, advocacy agencies and disability peak bodies.

The review of NDAP will be informed by:

- formal submissions received in response to the Discussion Paper
- consultation meetings and workshops
- the National Disability Advocacy Framework (NDAF) review process
- consultations by the Joint Standing Committee into the NDIS
- the Senate Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings
- the NDIS Quality and Safeguarding framework
- research of models of advocacy funded under the NDAP.

### Next steps

Feedback outlined in this report points to various changes that will need to be considered, including the way advocacy models are funded and delivered.

A final proposal for the reformed NDAP will be submitted to the Australian Government in mid-2017, to ensure a decision and process can be communicated to stakeholders, and the process implemented during the 2017-18 financial year.

DSS will seek further information from key stakeholders, as required, to ensure that interpretations and draft approaches are on the right track.

## **2. Purpose of the report**

This report summarises the responses received to the Discussion Paper, meetings with stakeholders by phone, in small groups and in large forums, and relevant research and review findings. It describes the themes and strategies identified, and provides some clarification of aspects of disability advocacy.

### **Acknowledgement**

DSS would like to thank the many informants who made a submission in response to the Discussion Paper or provided feedback in another forum. The insights provided are greatly appreciated and highly valued.

### **How will the feedback be considered?**

The findings of the consultations will help inform decisions about the best options for a reformed NDAP.

Feedback will also be considered in a range of other policy and program design contexts, including development of capacity building projects and improvements in the way that systemic issues are managed nationally.

This report will also be provided to existing NDAP providers for their consideration.

### **3. Key themes**

A summary of the main themes and ideas collected in the engagement with stakeholders is outlined below. Further detail is provided in Part 5, 'Summary of consultations'.

#### **Models of advocacy**

- Feedback about the optimal provision of service delivery models was mixed. Several stakeholders highlighted the benefits of providing only one or two models, while others considered this creates service gaps.
- The majority of submissions indicated a flexible, person-centred approach using different advocacy models depending on the needs of the individual is most beneficial.

#### **Improving access to advocacy supports**

- Many submissions indicated a need for increased funding for advocacy support for people with disability from: ATSI communities; CALD communities; rural, regional and remote locations, as well as people who are very socially isolated including those with communication difficulties and those in institutional care.
- Submissions also included a wide range of program design and service delivery ideas that would increase the accessibility of advocacy services to the groups above. Suggestions included offering outreach services, providing free translating and interpreting services, and having well developed referral networks.
- Funding for advocacy agencies which specialise in specific population groups was also largely supported.

#### **Improving the advocacy evidence base and coordination on systemic issues**

- Data collection and reporting was a key theme, with feedback noting a need for standardised reporting across Australia.
- Feedback highlighted the need for a national, stand-alone agency or mechanism to undertake a coordination role for systemic advocacy.

#### **The interface with the NDIS and addressing conflict of interest**

- The majority of submissions stressed the importance of continued funding for independent advocacy outside the NDIS.
- Feedback about conflict of interest, in delivering both independent advocacy and disability services, was mixed. Many submissions suggested that organisations funded to provide advocacy should not be funded through the NDIS as well. However, others suggested that some organisations will be well placed to deliver both advocacy and disability services - and this is acceptable, as long as the appropriate structures are in place, and the other services are not high-risk (i.e. delivering essential services such as accommodation).

## **Understanding and improving access to justice**

- Many submissions called for increased funding for legal advocacy to better support people with disability.
- Several submissions indicated that specialist disability Community Legal Centres (CLCs) are the most effective model of legal advocacy.

## 4. Sources of information

### DSS engage website

In April 2016, DSS released the Review of NDAP Discussion Paper via the DSS engage website, and called for submissions from key stakeholders and the general public. The Discussion Paper aimed to initiate discussion and generate ideas about what a reformed NDAP should look like and how it should work in an NDIS environment. The Discussion Paper sought feedback on five key areas:

- models of advocacy
- improving access to advocacy supports
- improving the advocacy evidence base and coordination on systemic issues
- the interface with the NDIS and addressing conflict of interest
- understanding and improving access to justice.

DSS also invited feedback on other significant issues and ideas that could improve the future delivery of disability advocacy through NDAP. In response to the Discussion Paper, DSS received 156 written submissions.

### Meetings with stakeholders

In addition to the call for written submissions, DSS held a number of consultation meetings with a range of stakeholders including people with disability, carers and family members of people with disability, advocacy agencies and disability peak bodies. The key areas identified in the Discussion Paper provided a structure for the meetings.

The major themes identified during these meetings were:

- concerns about current and future funding for advocacy
- the importance of advocacy remaining outside of the NDIS
- the need to focus on hard-to-reach groups that are marginalised and isolated
- the need for legal advocacy/training on legal issues
- the lack of knowledge of advocacy and advocacy services – and the need for promotion of advocacy, its availability and value in supporting people with disability
- the need for community capacity building
- the value of using technology to provide support to clients in rural and remote locations
- the importance of systemic advocacy.

Many of these themes were also identified in written submissions.

### Focused workshops

The Discussion Paper noted DSS would use the suggestions and ideas provided in submissions to identify topics for a series of targeted stakeholder workshops. These workshops, intended to clarify and refine some of the concepts and strategies raised during the submission process, will be held in March-April 2017.

## **Review of the National Disability Advocacy Framework (NDAF)**

In addition to written submissions and stakeholder workshops, the NDAP Review will also take into account feedback provided during the 2015-16 Review of the NDAF. Key themes identified during that process included:

- the need for advocacy to be independent, with conflicts of interest avoided
- provision of advocacy for all people with disability, regardless of their eligibility for NDIS funding
- the need for increased funding for advocacy
- detailed definitions of advocacy supports and who will be providing them
- the importance of systemic advocacy
- the need for improved data collection and reporting to provide accountability.

## **Information from consultations by Joint Standing Committee into the NDIS**

The Joint Standing Committee on the NDIS was appointed to inquire into and report on: the implementation, performance and governance of the NDIS; the administration and expenditure of the NDIS; and such other matters in relation to the NDIS as may be referred to it by either House of the Parliament.

In July 2014 the Joint Standing Committee released the *First progress report on the implementation and administration of the National Disability Insurance Scheme*. This report noted the importance of the role of advocacy services in ensuring quality plans and supporting participants in the planning process, and recommended that certainty regarding the role and support for advocacy services in the NDIS be urgently resolved through the Council of Australia Governments Disability Reform Council.

In March 2015 the Joint Standing Committee held a Public Roundtable in Canberra with a focus on the “Role of advocacy services in the NDIS”. Key issues raised by witnesses included:

- concerns about future funding (both Commonwealth and state)
- the fact that advocacy relates to much more than the NDIS
- the need for consultation with the advocacy sector
- gaps in advocacy coverage
- lack of quality data
- the importance of advocates being independent
- the critical need for advocacy in Aboriginal communities.

## **Senate Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings**

In November 2015, the Senate Standing Committee on Community Affairs released its report into violence, abuse and neglect against people with disability in institutional and residential settings.

The report included two recommendations related to advocacy:

**Recommendation 15** - that all levels of government acknowledge the vital role that formal and informal advocacy plays in addressing violence, abuse and neglect of people with disability. It went on to suggest a range of actions including increased training for people with disability to recognise violence, abuse and neglect – and further consideration of the Victorian Self Advocacy Resource Unit, with a view to roll out a similar approach across other states and territories.

**Recommendation 16** - that the NDAP implement the following recommendations:

- provide significant investment to NDAP funded advocates to deliver equitable access and representation of issues, and to match the increased demand for advocacy anticipated under the NDIS
- undertake a review to ensure delivered advocacy is appropriately spread across service types and complaint types, to ensure the most vulnerable are receiving advocacy
- increase funding for self-advocacy programs
- ensure that the current model of funding peak bodies does not inadvertently result in the closure of smaller specialist or local advocacy organisations
- improved coordination between the NDAP and the National Aged Care Advocacy Program.

### NDIS Quality and Safeguarding Framework

The NDIS Quality and Safeguarding Framework, released in February 2017, is designed to ensure high quality supports and safe environments for all NDIS participants. It seeks to help participants and providers access information and resolve issues quickly, and strengthen the capability of participants, the workforce, and providers to participate in the NDIS market.

The Framework articulates that independent individual and systemic advocacy, funded outside the NDIS, is one of the underpinning foundations of the Framework. It also recognises that independent advocacy services have a key role in assisting people with disability to access information and make decisions, and in protecting and promoting the rights of people with disability.

### Research of the models of advocacy funded under NDAP

In 2009, Jenny Pearson & Associates Pty Ltd undertook research and completed a report for DSS that considered the appropriateness, effectiveness and efficiency of the six models of advocacy; and identified key performance indicators that could be used to measure the success of different advocacy models.

Overall conclusions of the report were:

- NDAP should fund two main streams of advocacy – individual and systemic.
- Individual advocacy should be the primary model but should incorporate the flexible use of other models, such as self, legal and family advocacy, as appropriate to meet consumer needs.
- Specialist advocacy support should continue to be provided for people whose advocacy needs require specialist knowledge and skills, for example, people from

Culturally and Linguistically Diverse (CALD) or Aboriginal and Torres Strait Islander (ATSI) communities.

- There should be a structured pathway(s) for systemic issues identified by individual advocacy agencies to progress through systemic advocacy agencies.
- NDAP should be founded on:
  - consistent advocacy principles and standards of practice
  - national disability advocacy quality assurance and accreditation processes
  - collaboration and networking between agencies
  - accredited training and development opportunities for advocacy staff.

Some of the recommendations, such as the legislated quality assurance and accreditation processes, were implemented by DSS but the larger changes associated with the models of advocacy were not.

## 5. Defining advocacy and its interface with other supports

Advocacy for people with disability can be defined as speaking, acting or writing with minimal conflict of interest on behalf of the interests of a disadvantaged person or group, in order to promote, protect and defend the welfare of and justice for either the person or group by:

- acting in a partisan manner (i.e. being on their side and no one else's)
- being primarily concerned with their fundamental needs
- remaining loyal and accountable to them in a way which is empathic and vigorous (whilst respecting the rights of others)
- ensuring duty of care at all times.

### The interface of advocacy with other supports

Many stakeholders were concerned about a lack of clarity within the community and in government about what advocates do.

When considering the role of advocacy into the future, it is essential to have a clear understanding of the roles and responsibilities of other similar services for people with disability – including the National Disability Insurance Agency's (NDIA's) Local Area Coordinators (LACs) and Support Coordinators, and the Commonwealth Ombudsman.

It is important to recognise the unique role of advocacy and understand the limitations and restrictions of other roles. For example, NDAP advocates are independent and can act solely on the side of the person with disability. This differs from NDIS LACs (who have conflicts of interest due to their direct or indirect employment by the NDIA) and NDIS Support Coordinators (who have an interest in maintaining the funding relationship).

The Commonwealth Ombudsman (the Ombudsman) offers independence but is limited in scope – being restricted to dealing with complaints about Commonwealth entities including the NDIA. The role of the Ombudsman is not to identify people who may have complaints and support them to come forward, or to assist them to raise the complaint directly with the relevant organisation in the first instance. Feedback from the Commonwealth Ombudsman, via face to face meetings and their submission to *NDAP Review Discussion Paper*, indicates that:

*“any safeguarding system in the disability environment cannot operate optimally in the absence of a robust, dynamic and well-resourced advocacy system...”*

*We know from our work that even where government agencies and complaint bodies make every effort to be visible and approachable, there will likely remain instances where people with disability are unwilling or unable to make a complaint in the absence of a trusted source of support. This is a reality in many of the areas of our work where the most vulnerable people impacted by government administration are also the least likely to complain for a variety of reasons including fear of retribution or withdrawal of services. We find that the issues in these areas often only become apparent through the hard work of advocacy organisations, who either make complaints on behalf of individuals or bring broader systemic problems to us for consideration.<sup>19</sup>*

It is important that advocacy supports provided by NDAP:

- are complementary to other types of decision making and human rights support
- demonstrate minimal to no duplication of those other supports
- have the flexibility to adapt to changes as the NDIS matures.

The following table provides additional detail regarding the roles of NDAP advocates, NDIS LACs and Support Coordinators, and the Ombudsman.

**Table 1: Purpose, independence and focus of NDAP advocates versus other support roles**

Role	Purpose	Independence	Focus/ scope
NDAP Advocates	Provide people with disability with access to effective advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation.	Independent from service provision, sole interest is the client’s needs.  Some conflict of interest may arise where an advocacy provider is also delivering NDIS services.	<ul style="list-style-type: none"> <li>• All people with disability seeking advocacy.</li> <li>• No restrictions to issues that they can provide support for apart from limits of advocate’s knowledge, which can be supplemented through specialist assistance and referrals.</li> <li>• Presence in capital and regional cities and in remote areas.</li> <li>• If demand on an agency is high, priority is given to those who are most vulnerable in accordance with the organisation’s service access policy.</li> </ul>
NDIS Local Area Coordinators (LACs)	To assist people with disability, their families and carers to build and pursue their goals for a good life, exercise choice and control and engage with the Scheme; and ensure that people with disability can be supported outside the Scheme, by working with communities and mainstream services to build awareness, and to become more inclusive of the range of needs and aspirations of people with disability.	Employed by the NDIA (directly or indirectly) and considered to be an extension of the NDIA – therefore cannot be solely on the side of the person with disability.	<ul style="list-style-type: none"> <li>• Restricted to providing assistance to NDIS participants, or people with disability who approach the NDIA.</li> <li>• Unable to advocate for a person with disability beyond basic information, education and referral.</li> <li>• Unable to assist people with disability with complaints beyond information and referral.</li> <li>• The NDIS website includes the following: “<i>It is important to remember Local Area Coordinators do not provide case management, act as an advocate for the person with disability, and they cannot approve an NDIS plan<sup>2</sup>.</i>”</li> </ul>

<p>NDIS Support Coordinators</p>	<p>Assistance to strengthen participant’s abilities to coordinate and implement supports and participate more fully in the community.</p> <p>It can include initial assistance with linking participants with the right providers to meet their needs, assistance to source providers, coordinating a range of supports both funded and mainstream and building on informal supports, resolving points of crisis, parenting training and developing participant resilience in their own network and community.</p>	<p>As registered providers receiving funding from individual funding plans, they have an interest in maintaining the funding relationship and therefore have a level of conflict of interest.</p> <p>Note: the NDIA <i>Coordination of Supports – Information for Providers</i> document notes that “<i>The Support Coordinator should not be the provider of any other funded supports in the plan. This is necessary to ensure that there is no conflict of interest<sup>3</sup>.</i>”</p>	<ul style="list-style-type: none"> <li>• Supports are only provided to NDIS participants that have funding allocated to support coordination.</li> <li>• Support is limited to assisting with the management of services funded by their NDIS plan.</li> </ul>
<p>Commonwealth Ombudsman – Disability</p>	<p>Good public administration that is accountable, lawful, fair, transparent and responsive.</p> <p>Considers and investigates complaints from people who believe they have been treated unfairly or unreasonably by an Australian Government department or agency.</p>	<p>Independent entity from Government with no conflict of interest in providing support to people with disability.</p>	<ul style="list-style-type: none"> <li>• All Australians can approach the Ombudsman.</li> <li>• Restricted to dealing with complaints about Commonwealth entities including the NDIA.</li> <li>• Has an office in each capital city but no broader presence or outreach.</li> <li>• Role is not to support people to bring complaints to the Ombudsman.</li> <li>• The assumption is that in most cases, people will have already tried to address the complaint to the relevant agency before coming to the Ombudsman. For people with disability, this will often require advocacy support to some degree, both in dealing with the agency concerned and in working through the Ombudsman’s complaint process.</li> </ul>

## 6. Summary of findings

### Models of advocacy

*Background:* agencies currently providing advocacy through NDAP are funded for advocacy supports under different models: individual advocacy, self-advocacy, citizen advocacy, family advocacy, legal advocacy and systemic advocacy. There is no pattern or consistency in how much is funded to each model in each region, and this means there are gaps in the choice of models and the availability of support for people with disability.

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

Feedback from several disability advocacy agencies highlighted the benefits of limiting funding to only one or two models of support, which included:

- an enhanced skillset/ staff developing skills and experience in a particular area
- ability to establish referral networks.

It was also noted that people with disability may benefit from engaging with smaller style, community based organisations which provide one or two models:

*“For many people with disabilities, accessing larger organisations can feel overwhelming (be a barrier) and may lead to them not accessing any advocacy support at all<sup>14</sup>.”*

The key concerns of stakeholders were that options of support remain available and that the expertise of advocacy agencies in different models is not lost.

#### **What are the drawbacks?**

Numerous submissions from a range of individuals, agencies and other stakeholders outlined possible service gaps as the main drawback when agencies are funded to provide only one or two models.

As an example, the Ability Incorporated Advocacy Service (AIAS) noted that:

*“AIAS is funded to deliver 3 models of support; individual, family and self advocacy. If we were only funded for 1 or 2 models, the service we provide will not be as effective. For example, a consumer may initially require individual advocacy assistance at a meeting with a service provider, but are able to advocate for themselves when given self advocacy training. Many of our consumers, through our self advocacy get together, are empowered with information and activities that enable them to assert their rights.*

*If advocacy agencies are flexibly funded, then advocacy services can support all forms of advocacy matters, including systemic and legal. This would eliminate gaps in service and support.”<sup>15</sup>*

Similarly, Melbourne East Disability Advocacy expressed concerns that being limited to two advocacy models can, at times, impact their ability to have a holistic approach.

However several organisations, such as Advocacy for Disability Access and Inclusion, suggested that these risks can be managed through liaison, collaboration and referrals between different providers.

In line with this thinking, Queensland Advocacy Inc noted:

*“It is more useful to examine the quality of networking, collaboration and cooperation between advocacy organisations and the community legal sector to determine the effectiveness and efficiencies that are currently present rather than to assume that specialisation or singular focus on a model of advocacy is less valid or somehow lacking.”<sup>6</sup>*

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

Feedback from advocacy agencies about valuing and supporting various models while ensuring equitable access included:

- the need for an increase in funding
- the importance of networking and collaboration between advocacy organisations
- use of technology
- NDAP contracts to be flexible – *“enabling organisations to reach outcomes by being responsive to need, rather than being constrained by particular ‘deliverables’.”<sup>7</sup>*
- funding for travel – *“A number one funding priority is for adequately funded travel (and associated costs) to deliver services in all regional, remote and very remote locations as it is the right of all people in those areas to have access to quality services”<sup>8</sup>.*

The majority of submissions suggested flexible models that focus on human rights and use different advocacy models are most beneficial – increasing choice and improving outcomes for people with disability.

National Disability Services noted that too much specialisation in the allocation of advocacy funding is confusing and creates barriers, and indicated their support for the funding of a smaller number (less than the current 58) of generalist advocacy services across Australia:

*“These services need to be well-resourced, particularly with good ICT capability, so they can communicate well with people seeking assistance even when they live some distance away.”<sup>9</sup>*

However, several submissions expressed concerns at the prospect of NDAP providers being required to have knowledge and expertise across all models of advocacy.

*“This is not realistic, and unfairly favours a small number of large providers. Furthermore, it threatens to create a system based on mediocrity, not expertise, and might require individual agencies to maintain unsustainable staffing levels.”<sup>10</sup>*

A number of organisations and family members of people with disability suggested a hub and spoke model – with a centralised hub helping to link individuals to the most appropriate service. The Sector Support Development Network suggested that:

*“knowledge brokers in the ‘hub’ would link the person with disability to an appropriate advocacy provider, and if the person requires urgent advocacy supports for which there is capacity the ‘hub’ are able to purchase these services with discretionary funds. This system ensures quick and equitable access to advocacy supports. The centralised hub could monitor wait lists and broker partnership arrangements in remote locations, model best practice for working with special needs groups, distribute learning and promotion materials and collect data on service use, which*

*may in turn be used to support service providers to better support individuals with disability.<sup>11</sup>*

Other submissions suggested it would be sufficient to establish a hotline with calls diverting to the nearest NDAP provider. It was noted that such a service would need to ensure that calls from mobiles are free.

More broadly, the Office of the Public Advocate QLD suggested that the Australian Law Reform Commission's *National Decision-Making Principles* (the Principles) should be incorporated into the NDAF<sup>1</sup> and NDAP. It is suggested that the incorporation of the Principles would "*maximise the participation and right to autonomy of people with impaired decision-making capacity, and assist them to make their own choices in the advocacy process<sup>12</sup>.*"

### Improving access to advocacy supports

*Background:* previous NDAP evaluations, current data collection and stakeholder feedback confirms that there are target groups within the population of people with disability that have to deal with additional barriers to accessing support. As a consequence the following questions were included in the Discussion Paper to gather feedback to inform the approach to address this issue.

#### How do we improve access for:

- **people with disability from Aboriginal and Torres Strait Islander (ATSI) communities and their families**
- **people with disability from culturally and linguistically diverse (CALD) communities and their families**
- **people with disability in rural, regional and remote locations**
- **people who are very socially isolated including those with communication difficulties and those in institutional care?**

Broad feedback suggested that access to advocacy could be improved by:

- increased funding to support these groups
- cultural competence and other training and capacity building of the sector
- use of hub and spoke models that enable advocacy organisations to have a local presence<sup>13</sup>.

The benefits of specialist advocacy agencies were argued in several submissions. As an example, Communication Rights Australia, the Disability Discrimination Legal Service and Leadership Plus stated that:

*"Specialist advocacy agencies have the skills and expertise to respond to the needs of the community they represent (including all those groups above)... Generalist advocacy services do not always have the relevant skills<sup>14</sup>".*

Suggested specialist areas included:

- ATSI
- CALD
- Intellectual Disability

---

<sup>1</sup> The National Decision Making Principles have been incorporated into the draft Transitional NDAF.

- Deafblindness
- Acquired Brain Injury
- Spinal Cord Injuries
- Autism
- Physical Disability
- the Lesbian, Gay, Bi-sexual, Transgender and Intersex community

Other stakeholders suggested that generalist advocacy agencies could be encouraged to employ advocates who specialise in specific population groups. For example, National Disability Services suggested that funding decisions for generalist advocacy organisations take into account the location of local ATSI and CALD communities. National Disability Services went on to note that this:

*“will only be part of the solution to the inadequate access these communities have to culturally-appropriate advocacy support. As it is impossible to predict which advocacy services people from these communities will approach, all advocacy services should have the skills and capability to assist. This requires advocacy services to be networked, with the expectation that they collaborate to ensure people seeking assistance get access to the most appropriate support<sup>15</sup>”.*

### ATSI communities

Many submissions outlined the need to provide culturally appropriate services, offering face to face and flexible options to support clients.

Aboriginal & Torres Strait Islander Disability Network of Queensland (ATSIDNQ) noted that improved access is:

*“heavily reliant on the appeal of the service/advocacy organisation to the Aboriginal and Torres Strait Islander population locally. As advocacy touches on many contentious and potentially emotive issues, providers with a local presence who are familiar with local knowledge and existing relationship are much better placed at building the trust required for a successful advocacy process.*

*There is an opportunity to engage with the community to see young people trained and employed in local community programs. Use programs already designed within communities that have extensive lists of young people who have engaged with leadership and advocacy programs. Work within a strengths based framework to provide education and employment to existing young Indigenous Leaders in their own communities<sup>16</sup>”.*

Another ATSI organisation indicated that access for their communities is best improved by either funding Aboriginal organisations directly in the local area, or by partnering with/subcontracting to those organisations to access Aboriginal communities.

Other feedback to this question commented on the need to:

- use an outreach approach
- *“fund capacity building of advocacy organisations to ensure cultural competence and ensure that employees that can provide culturally appropriate advocacy supports<sup>17</sup>”.*

### CALD communities

Submissions were received from several CALD specific organisations including Federation of Ethnic Communities' Councils of Australia (FECCA), Multicultural Disability Advocacy Association and the Ethnic Community Services Cooperative.

Feedback from these and other organisations indicated that “*developing a culturally aware and sensitive workforce, including those providing disability advocacy is vital in assisting people from migrant and refugee backgrounds*”<sup>18</sup>.

More specific suggestions for improving access for people with disability from culturally and linguistically diverse (CALD) communities and their families included:

- advocacy agencies to develop cultural competence at the level of the individual worker and throughout all organisational systems<sup>19</sup>
- education about barriers to CALD communities accessing disability supports<sup>20</sup>
- establishing links and communication with local CALD groups and organisations<sup>21</sup>
- funded advocacy services be required to demonstrate an understanding of complex issues facing CALD (and ATSI) people with disability<sup>22</sup>
- development and dissemination of resources in a range of languages, including workshops for CALD communities on disability rights and services available to uphold these rights<sup>23</sup>
- development of culturally or language specific peer networks for people with disability from CALD communities to build capacity and enhance self advocacy in these communities.<sup>24</sup>

Many submissions identified free translating and interpreting services as an essential component of working effectively with CALD communities.

### Rural, regional and remote locations

Submissions from a range of sources highlighted a need for additional funding to adequately service clients in rural, regional and remote locations.

A number of organisations, including the Commonwealth Ombudsman and the ME/CFS and Lyme Association of WA, Inc., touched on the need to use technology to expand geographical reach – including via phone, Skype, email and confidential online chat forums.

Midland Information Debt and Legal Advocacy Service Inc. also supported the use of technology, but flagged its limitations:

*“Despite the benefits of using technology as a means of engaging people with disability, this may not always be appropriate and is dependent on the ability of the person, the availability of the technology and the operational costs that a person may incur. The use of technology should not substitute the importance of face-to-face interactions with an Advocate”*<sup>25</sup>.

Other submissions focussed on the imperative for “*people with disability in rural, regional and remote locations to have access to local advocacy services*”<sup>26</sup>.

### Socially isolated including those with communication difficulties and those in institutional care

Several submissions touched on the significant barriers that this vulnerable group can face when accessing advocacy and other supports.

An increase in funding to support this group (and the groups above) was suggested in a number of submissions, including by the Victorian Rural Advocacy Network which indicated that a: *“properly funded active outreach model can be used to identify people who are socially isolated and support them to have a voice<sup>27</sup>”*.

Capricorn Citizen Advocacy outlined the important role that citizen advocacy can play in supporting this group.

*“A long proven way of providing advocacy and other supports to people to very socially isolated people is Citizen Advocacy. This model is a very intentional process of assessing unmet needs and vulnerabilities of people with disabilities (including those in these circumstances). It is accompanied by a careful ‘matching’ of each individual with an everyday citizen who possesses competencies, personal qualities such as a sense of justice and compassion and who has their own network of family and friends in the community<sup>28</sup>.”*

Advocacy Tasmania Inc. suggested that the development and use of communication aides and devices to assist people with communication disorders is vital, along with a focus on better skilled services and employment of qualified staff.

More specifically, the Deafblind Association (NSW) Inc. indicated that due to the communication issues facing this group, Deafblind people are best supported by specialised expert advocacy as opposed to generic advocacy.

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

Examples of strategies or models that have worked include:

- person-centred, issues-based individual advocacy
- diverse teams of advocates
- basing an advocate in a known and reputable Aboriginal organisation, where they can travel with colleagues and refer to other organisational services as required
- ensuring a good fit between the advocate and person requiring support
- offering outreach services
- having well developed referral networks
- providing free translating and interpreting services
- having the ability to seek out vulnerable people who would otherwise never speak out<sup>29</sup>
- having skilled staff who seek to understand a range of factors, including the:
  - *“person’s vulnerability, life experiences, values, beliefs and current situation*
  - *the impact of the person’s impairment*
  - *the impact of culture, language and religion*
  - *the broader social, legislative, policy and systems that impact on the person and their family<sup>30</sup>.”*

Examples of strategies that do not work include:

- a one size fits all approach
- automated telephone systems/ call centres
- advocacy at a distance/ occasional visits to remote communities
- pamphlets written in English or left in waiting rooms at hospitals.

### **Improving the advocacy evidence base and coordination on systemic issues**

*Background:* systemic advocacy is funded inconsistently across jurisdictions by NDAP. There isn't a regular and consistent approach to sharing information of systemic issues between NDAP agencies or with stakeholders such as governments and other entities focused on human rights of people with disability.

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

Data collection and reporting was a key theme, with feedback noting a need for:

- standardised reporting, consistent across Australia
- appropriate data collection software
- a robust framework for data analysis
- case-study data collection – *“It is important that both individual and systemic advocacy data collection provide more story-based narrative that effectively describes what is happening to the people accessing services and identifying the human rights issues that are at stake<sup>31</sup>.”*

The need for a national, stand-alone agency or unit to undertake a coordination role for systemic advocacy was a significant theme. The suggested role of such an organisation included:

- collation of data, trends and gaps – with quarterly or six monthly reports to be released to the appropriate organisations, including the NDIA
- communication with Government about identified issues
- communication and networking with the sector
- development of resources and professional development.

Many organisations suggested that Disability Advocacy Network Australia (DANA), or an organisation like DANA, could be suitable for this role.

Some stakeholders highlighted the important role of systemic advocacy operating at different levels (local, regional and state and territory). As an example, Synapse/ Brain Injury Association of NSW 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<sup>32</sup>.”*

Some submissions noted the importance of having a connection between advocacy agencies. Gold Coast Disability Advocacy provided an example of one such successful model currently operating in Queensland:

*“Advocacy organisations of various differing models in Queensland, though independent of each other, have on their own initiative formed a connectedness*

*through Combined Advocacy Groups of Queensland and through membership of the peak body DANA. These linkages provide an opportunity to identify systemic issues from advocacy work that is being undertaken on an individual basis and ensure that systemic advocacy is driven by people with disability<sup>33</sup>.*

**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?**

Suggestions to work more effectively with other stakeholders included:

- face-to-face conferences/seminars
- regular systemic advocacy meetings
- regular communication/networking
- provision of webinars
- teleconferences
- professional development opportunities
- a web-based notice board/online forum for systemic advocacy issues
- resource units or peak bodies that can disseminate regular updates and provide information about opportunities for collaboration.

Many stakeholders reported that funding to undertake these activities should be provided as part of an advocate’s role.

### **The interface with the NDIS and addressing conflict of interest**

*Background:* the introduction of the NDIS is providing opportunities and challenges for people with disability and advocacy agencies. The NDIS will fund some decision-making supports and capacity-building for people with disability, but this will be largely for NDIS participants and people accessing the Information, Linkages and Capacity Building services. Policies and processes need to be developed to assist all stakeholders to understand expectations about conflicts of interest and how they can be managed.

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

Some feedback indicated that organisations funded to provide advocacy should not also be funded through the NDIS. Feedback from a person with disability who supported this view stated that: *“If an organisation provides, support, accommodation, or other forms of assistance to people with disabilities they cannot and should not be funded for advocacy work because of the obvious conflict of interest<sup>34</sup>”.*

Consumers of Mental Health WA also supported the separation of general advocacy from the NDIS in order to:

- *“Enable advocates to be independent from both the NDIS when speaking up on behalf of individuals about the NDIS*
- *Foster trust in independent advice for individuals seeking information, advice and support on applying for the NDIS*
- *Prevent constraints on disclosure of systemic advocacy concerns to systemic advocacy organisations, and by systemic advocacy organisations that are also funded by NDIS*
- *Prevent conflicts associated with being both a service provider and an advocate*
- *Prevent risk of losing free of charge advocacy for people to uphold community and service rights and participation*
- *Prevent risks that advocacy is prioritised on a fee basis, rather than a triage approach (e.g. that is free to prioritise service access for serious issues such as abuse, neglect and restrictive practices)<sup>35</sup>”.*

However, others suggested that some organisations will be well placed to deliver both advocacy and services, and that this is appropriate as long as the appropriate structures are in place. Suggested steps or organisational structures to reduce conflicts of interest included:

- rigorous organisational structures and governance measures
- policies and procedures around the declaration of both real and perceived conflicts of interest
- conflict of interest registers
- adequate complaints procedures
- preventing boards of management from having members who have obvious conflicts of interests, such as direct links to their funding bodies<sup>36</sup>
- having advocacy services located apart from NDIS services.

The Disability Council NSW suggested that: *“NDAP should fund capacity building for organisations to assist them to manage potential conflicts of interest where they are a NDAP provider and NDIS provider, including funding and assistance to update conflict of interest management procedures in line with best practice<sup>37</sup>”.*

The Intellectual Disability Rights Service commented that Community Legal Centres apply strict guidelines and practices to manage conflicts of interest and that these could be considered in response to this question<sup>38</sup>.

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

The majority of submissions from a wide range of stakeholders, including people with disability and their family members, stressed the importance of continued funding for independent advocacy outside of the NDIS. As an example, Developmental Disability WA indicated that in their view: *“funding for advocacy organisations need not and should not be tied to the arrival of the NDIS. There will always be people who will not be eligible for the NDIS but who will seek and access advocacy and this must be available for them<sup>39</sup>”.*

Citizen Advocacy Trust of Australia also supported the continuation of independent advocacy, noting that funding should be *“as far away from funding for service provision and*

*the NDIS as possible so that advocates can act in the best interests of people with disabilities without fear of losing funding or jobs<sup>40</sup>.*

The submission from Young People in Nursing Homes National Alliance indicated that the function of advocacy needs to be “*well defined as a community safeguard and support that is separate to the NDIS’ market*” and suggested that new NDAP contracts “*should promote a clear definition of advocacy that cannot be commodified by the NDIS market and diluted by a transfer to individual packages*”.

Another theme that emerged, in relation to gap avoidance in the delivery of NDIS services and advocacy funded under NDAP, was need for greater clarity in relation to the interface between both programs. More specifically, the Commonwealth Ombudsman noted:

*“It will also be important to further explore, and settle the issue of whether organisations funded by the NDIA to deliver Information, Linkages and Capacity (ILC), decision support and pre-planning services can also be funded by the Commonwealth, state or territory government to act as an advocacy organisation”.*

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

Suggested policies and strategies included:

- utilising the United Nations Convention on the Rights of Persons with Disabilities as the basis for laws and organisational policies
- ensuring NDAP has a client focussed approach with enforced service delivery standards
- clear guidelines of rights and responsibilities of people with disability and other stakeholders (i.e. service providers) in various formats – both clinical and generalised language
- talking to people with disability about their rights in appropriate language
- training for personnel on disability rights
- provision of advocacy being independent from any other service provision
- unhindered access to advocates – “*Advocates to have unhindered access to people with cognitive and communication disabilities even if it is inconvenient for the people who work with them or live with them<sup>41</sup>”.*

### **Understanding and improving access to justice**

Background: Legal advocacy funded by NDAP is currently only available in two states. The definition of legal advocacy and “access to justice” varies widely. Types of legal advocacy can be divided into the following four activities:

- legal advice and/or representation from a legal professional
- community legal education programs and information services
- non-legal support, including but not limited to organising referrals, facilitating meetings, navigating processes, interpreting or translating information
- advocating for law reform or justice-related systemic issues.

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

Responses included:

- representation at the AAT appeals process for NDIA related issues
- representation at Centrelink review processes
- counsel for criminal court proceedings
- family law
- representation for child protection hearings
- guardianship orders
- employment discrimination in the interview or hiring stages, or through unfair dismissal and exclusion from work practices
- education discrimination
- restrictive practices
- Human Rights Commission hearings
- compensation
- complaints
- housing
- debt and financial management.

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

Identified barriers included:

- communication/literacy issues
- cost of legal support
- waiting lists
- lack of understanding of the legal system
- fear of losing supports if they speak out
- physical barriers such as poor access to buildings<sup>42</sup>
- cultural and attitudinal issues among legal professionals and in the broader community<sup>43</sup>
- lack of awareness and understanding of the needs of people with disability by the court system, and an inability to cater to individual need
- police not identifying an offender/victim as having a disability
- education for people with disability: "*People with disabilities must firstly understand their rights, before they can press them.*"<sup>44</sup>

Many submissions called for increased funding for legal advocacy to better support people with disability overcome these and other barriers.

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

Suggested components for effective models included:

- free of charge
- works in conjunction with the mainstream justice system

- takes a multidisciplinary approach (offering legal and non-legal services)
- ensures access to suitably qualified legal practitioners
- available in all jurisdictions
- ability to visit communities to talk about legal support and advocacy that is available
- provides legal education for people with disability, justice professionals and wider community<sup>45</sup>
- takes a holistic approach to problems.

Several submissions indicated that specialist disability Community Legal Centres (CLCs) are the most effective model of legal advocacy.

*“It is highly efficient and effective for advocacy organisations to network and cooperate with community legal centres and for advocacy organisations to have referral points to CLCs. The benefits of CLCs that specialise in a particular area of disability representation is that expertise can be built upon; people with disability know where they can be best represented; family members, advocates, the Statutory bodies, service providers, government departments and Tribunals know where to refer people for representation and where if necessary they need to liaise, and a specialist CLC can then provide training and information to other CLCs as part of the community legal education projects...<sup>46</sup>.”*

## 7. References

- <sup>1</sup> Submission to NDAP Review Discussion Paper – Commonwealth Ombudsman
- <sup>2</sup> NDIS website – Local Area Coordination - [NDIS website - Local Area Coordination](#)
- <sup>3</sup> [NDIA – Coordination of Supports – Information for Providers – December 2015](#)
- <sup>4</sup> Submission to NDAP Review Discussion Paper - Midland Information Debt and Legal Advocacy Service Inc.
- <sup>5</sup> Submission to NDAP Review Discussion Paper - Ability Incorporated Advocacy Service
- <sup>6</sup> Submission to NDAP Review Discussion Paper - Queensland Advocacy Inc
- <sup>7</sup> Submission to NDAP Review Discussion Paper - Side By Side Advocacy Incorporated
- <sup>8</sup> Submission to NDAP Review Discussion Paper – Independent Advocacy in the Tropics
- <sup>9</sup> Submission to NDAP Review Discussion Paper – National Disability Services
- <sup>10</sup> Submission to NDAP Review Discussion Paper - Information on Disability & Education Awareness Services Inc.
- <sup>11</sup> Submission to NDAP Review Discussion Paper – Sector Support Development Network
- <sup>12</sup> Submission to NDAP Review Discussion Paper – Office of the Public Advocate (QLD)
- <sup>13</sup> Submission to NDAP Review Discussion Paper – Speak Out Advocacy
- <sup>14</sup> Submission to NDAP Review Discussion Paper – Communication Rights Australia, the Disability Discrimination Legal Service and Leadership Plus
- <sup>15</sup> Submission to NDAP Review Discussion Paper – National Disability Services
- <sup>16</sup> Submission to NDAP Review Discussion Paper - Aboriginal & Torres Strait Islander Disability Network of Queensland (ATSIDNQ)
- <sup>17</sup> Submission to NDAP Review Discussion Paper - Disability Council NSW
- <sup>18</sup> Submission to NDAP Review Discussion Paper - Federation of Ethnic Communities' Councils of Australia
- <sup>19</sup> Submission to NDAP Review Discussion Paper - AMPARO Advocacy
- <sup>20</sup> Submission to NDAP Review Discussion Paper – Advocacy Tasmania Inc
- <sup>21</sup> Submission to NDAP Review Discussion Paper – Advocacy Tasmania Inc
- <sup>22</sup> Submission to NDAP Review Discussion Paper - Ethnic Disability Advocacy Centre
- <sup>23</sup> Submission to NDAP Review Discussion Paper – Ethnic Community Services Co-operative
- <sup>24</sup> Submission to NDAP Review Discussion Paper - Disability Council NSW
- <sup>25</sup> Submission to NDAP Review Discussion Paper - Midland Information Debt and Legal Advocacy Service Inc.
- <sup>26</sup> Submission to NDAP Review Discussion Paper - Victorian Rural Advocacy Network
- <sup>27</sup> Submission to NDAP Review Discussion Paper - Victorian Rural Advocacy Network
- <sup>28</sup> Submission to NDAP Review Discussion Paper - Capricorn Citizen Advocacy
- <sup>29</sup> Submission to NDAP Review Discussion Paper - Citizen Advocacy South Australia Incorporated (CASA)
- <sup>30</sup> Submission to NDAP Review Discussion Paper - AMPARO Advocacy
- <sup>31</sup> Submission to NDAP Review Discussion Paper - Ethnic Disability Advocacy Centre
- <sup>32</sup> Submission to NDAP Review Discussion Paper - Synapse/ Brain Injury Association of NSW
- <sup>33</sup> Submission to NDAP Review Discussion Paper - Gold Coast Disability Advocacy
- <sup>34</sup> Submission to NDAP Review Discussion Paper - Cheryl McDonnell
- <sup>35</sup> Submission to NDAP Review Discussion Paper - Consumers of Mental Health WA
- <sup>36</sup> Submission to NDAP Review Discussion Paper – AMPARO Advocacy
- <sup>37</sup> Submission to NDAP Review Discussion Paper - Disability Council NSW
- <sup>38</sup> Submission to NDAP Review Discussion Paper - Intellectual Disability Rights Service
- <sup>39</sup> Submission to NDAP Review Discussion Paper - Developmental Disability WA
- <sup>40</sup> Submission to NDAP Review Discussion Paper - Citizen Advocacy Trust of Australia
- <sup>41</sup> Submission to NDAP Review Discussion Paper - Cheryl McDonnell
- <sup>42</sup> Submission to NDAP Review Discussion Paper - Disability Advocacy and Complaints Service of South Australia Inc.
- <sup>43</sup> Submission to NDAP Review Discussion Paper – Disability Advocacy Network Australia
- <sup>44</sup> Submission to NDAP Review Discussion Paper - Communication Rights Australia, the Disability Discrimination Legal Service and Leadership Plus

---

<sup>45</sup> Submission to NDAP Review Discussion Paper – Disability Advocacy Network Australia

<sup>46</sup> Submission to NDAP Review Discussion Paper - Queensland Advocacy Inc.