

**National disability advocacy program review -  
June 2016**

**Spinal Cord Injuries Australia Policy and Advocacy Team**



21/06/2016

## **National Disability Advocacy Program Review**

### **Background**

It is to be expected that this review does not indicate a decreased focus on advocacy. On the contrary, the important role of independent advocacy has been affirmed by the Commonwealth Government in its commitment to maintain a strong and effective programme of independent advocacy for all people with disability, into the future. The Government recognises that outside of the NDIS – and within – people with disability will continue to need access to every type of advocacy service.

The most significant reason for a review is the rollout of the NDIS. The new models of service delivery, market development, and change in opportunities for people with disability as a consequence of the roll-out, flow on to influence what types of advocacy need to be provided within the NDAP, and what will be provided by the NDIS to NDIS participants. It will also impact on the advocacy services provided by organisations and the types of resources in our communities that are responsible for ensuring access and inclusion and the human rights of people with disability.

The rollout of the NDIS is also leading to change in the way disability advocacy is funded across Australia by states and territories with many jurisdictions abrogating their responsibilities by removing advocacy funding altogether during the transition to the NDIS.

The vision for NDAP

Spinal Cord Injury Australia's (SCIA) 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; and
- Includes a consistent and equitable funding model

### **Spinal Cord Injuries Australia's Submission**

SCIA welcomes the opportunity to contribute this submission to the DSS review of the NDAP. SCIA has been providing individual and systemic advocacy for people with spinal cord injury and similar physical conditions for many years and is funded for individual and systemic advocacy under the NDAP. SCIA believes every type of advocacy provided should be person centred and done in collaboration with the person, and/or their family, carer or friends as requested or deemed appropriate.

SCIA's policy and advocacy services have obtained positive outcomes for people with disability, using individual or systemic advocacy, through reactive and/or proactive activities. SCIA believes the rolling out of the NDIS will be of great benefit to eligible people with disability, their families and carers. However, SCIA anticipates there will be a significant demand for all advocacy services due to the expansion of current and development of new disability support services, as well as people with disability encountering issues when pursuing their goals under the NDIS. Furthermore, people with disability may encounter barriers and discrimination when trying to access the community, education, employment, transport, housing and accommodation to name a few. And advocacy services need to be available to all people with disability, their families and carers, regardless if they are accessing a service like the NDIS or not.

## Questions:

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

#### **Answer:**

People with disability, their families and carers benefit when agencies are funded to provide only one or two models of support by receiving a specialised or focused advocacy service. Each advocacy agency should be able to analyse the issue with the aim of addressing it to meet the needs of the person with disability to ensure their human rights are maintained and upheld. The advocacy agency providing one or two models of support can also refer and/or work in collaboration with the client's family and/or another specialist advocacy agency if required to provide a different type of advocacy as needed to ensure they get the most appropriate outcome for the client.

Regardless of the number or model types of support being offered or provided, the advocacy agency model and the advocates must have appropriate knowledge of the various types of advocacy, a good understanding of the disability sector and appropriate negotiation skills. Some advocacy agencies have been operating for a number of years and have developed advocacy knowledge, expertise and resources that can benefit people with disability, their family and carers. This can increase the chances of obtaining a positive outcome when trying to address the issue.

The principle behind advocacy support for people with disability is equitable social access across all aspects of life. With this in mind, advocacy support should be flexible and provided with a person centred approach. Therefore, DSS should consider greater flexibility in how it supports organisations that provide advocacy services allowing funded organisations to offer a broader range of advocacy services i.e. less emphasis on the type of advocacy provided; greater emphasis on a rights-based approach to access to services with a focus on measuring success through positive outcomes for people with disability.

It needs to be recognised that a percentage of people with disability also have a secondary condition (e.g. acquired brain injury or mental illness) which can significantly affect the way they communicate or understand the issues they are confronted with.

Having a specialised service enables people with disability, their families and carers to feel secure and dignified when expressing their concerns.

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

### **Answer:**

The drawbacks may be noticed if the client requires a different type of advocacy service than the one or two models that the chosen advocacy agency can provide. For instance, if after an initial client-advocate meeting it is identified that the client requires a different type of advocacy model than the type that the chosen agency can provide, another agency must be sought. However, an agency providing the required advocacy model may not be available in the client's location. Even if an advocacy agency that *can* provide the required model is available, it may have a waiting list which will create a delay in clients being assessed for service, which will delay getting the issue or complaint addressed.

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

### **Answer:**

A great deal of advocacy requested is initially by phone or email, although systemic advocacy issues may be raised by mail, in a meeting or through various disability sector networks, email groups and social media. With regard to the exchange of information, email communication is also a very important tool with the different types of advocacy support. Although some people won't have access to online services for various reasons e.g. lack of funding to purchase computers or Internet services, or the unavailability of the Internet in some rural or remote areas (although the NBN is gradually rolling out across Australia). However, when this is the case, traditional mail delivery services could be used, although not ideal due to the time it takes.

Current and emerging technologies, such as Skype and other web-based interfaces, could be used to facilitate equitable access to individuals regardless of their location. Again, this would be dependent on the access to technology and internet availability. The DSS via NDAP could provide the funding, trial and/or evaluate the usage of such internet technologies to ensure people with disability have been provided with the equipment and internet services to be able to access all advocacy models regardless where the individuals and the advocacy agencies are located.

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

- **people with disability from Aboriginal and Torres Strait Islander communities and their families?**
- **people with disability from culturally and linguistically diverse 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?**

**Answer:**

As the previous question (1) seeks answers to issues for advocacy agencies that deliver only one or two advocacy models, question 2.1 possibly highlights the need for “specialist” advocacy agencies that only deliver one or two advocacy models to meet the needs of people in the categories listed above. SCIA believes that some advocacy agencies might find it difficult to provide individualised, fit for purpose advocacy to meet the complex needs of people in all of the different categories, especially to meet the cultural needs of people with disability from Aboriginal and Torres Strait Islander (ATSI) communities.

Furthermore, as people with disability are expected to have increased choice and control of their services, people with disability from ATSI communities may prefer to choose advocacy agencies that specialise in meeting both their cultural and advocacy needs.

Where possible, SCIA advocates also work with their clients to self—advocate for their future needs. When it is recognised that an advocacy client has developed these skills, they may seek to become ‘ambassador advocates’ who can be responsible to identify and represent other people with disability, their families and carers. The DSS through NDAP could provide funding, further training and support for people with disability to participate and contribute within or to the wider community.

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

**Answer:**

SCIA believes the current strategy is working, and recurrent block funding should continue to be provided to existing long-standing advocacy agencies, of whom have developed expertise, knowledge and resources. However, it can be difficult to meet continuous or periods of high demand for individual advocacy services, which can require the advocacy agencies to create (and manage) client wait lists. SCIA suggests that there needs to be an increase in funding to support the current and future demand for advocacy services.

Furthermore, SCIA strongly suggests extra government funding be provided for the setup, training and usage of telecommunication technologies for advocacy agencies to use with the specific client categories when deemed appropriate. The usage of such technologies should facilitate a quicker response and better outcome for clients in conjunction with reducing the financial costs and resources in travel, accommodation and wages etc for face-to-face visits, particularly in rural, regional and remote locations.

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

**Answer:**

As there are a number of state and territory funded advocacy agencies that provide individual and/or systemic advocacy, it is difficult if not impossible to know what systemic advocacy issues are being worked on by the advocacy agencies unless they report the activities in newsletters, or there is collaboration between two or more agencies on the systemic issue.

However, the work of systemic advocacy may also include writing submissions to reviews, discussion papers and inquiries, of which the submissions are often publicly available on a website of the organisation undertaking the review, discussion paper or inquiry or on a website of the advocacy agency making the submission. Some advocacy agencies have representatives on various government, disability and community advisory committees which provides the opportunity to receive information from government departments and agencies, their activities and services of which might require the advocacy agencies to take action to address the systemic issues.

A mechanism that could be used to ensure information on systemic issues gets to the right people and organisations, might be for DSS to set up a web-based repository where advocacy agencies (or possibly other organisations) could post systemic advocacy issues. The systemic advocacy information would be shared when advocacy agencies have started the action which would enable other advocacy agencies to support the systemic advocacy by providing information and resources if it had addressed a similar systemic advocacy issue, or offer to work in collaboration with the advocacy agency, help share resources. There should be a forum for the sharing and communicating of systemic advocacy work by organisations with responsibility given to the peak representative Disability Advocacy Network Australia. It provides an avenue for dialogue that can then be used to pass on to networks.

This process could reduce the workload and use of resources by negating the need to duplicate systemic advocacy already undertaken on the same issue. This may also achieve a quicker and improved systemic outcome, and the activities of the systemic advocacy and information can be regularly updated on the web-based repository until completed.

Knowledge is power; any strategies that support empowering people with disability through information sharing, education, training that results in capacity building, particularly in areas with little or no service provision, is a positive outcome. Regular consultation with people with disability, their family, friends, carers and their representative organisations on government policy reforms can bring about better outcomes for everyone.

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

- **disabled people's organisations (DPOs)**
- **the Australian Human Rights Commission**
- **Ombudsman organisations**
- **aged care advocacy organisations**
- **state disability advocacy organisations**
- **peak bodies?**

**Answer:**

Disability advocacy organisations could be helped to work with a wide range of other organisations with similar aims such as the ones listed above, by using the suggested web-based notice board for systemic advocacy issues. Or having the above-mentioned organisations also list their current systemic advocacy issues, and/or if they seek information and/or feedback on their systemic advocacy issues being worked on by the advocacy agencies.

As DSS undertakes regular audits and performance reviews of funded advocacy agencies, DSS would therefore be aware of the systemic advocacy being undertaken by advocacy agencies and DSS is in a position to identify the common and/or current advocacy issues. The DSS could produce a regular report containing the list and/or ratio of individual and/or systemic advocacy issues. This report could also be useful for enabling disability advocacy agencies to work in collaboration with a range of other organisations, as well as enabling the DSS to appropriately fund targeted systemic advocacy issues with regular and/or with one-off grants etc.

Where there are issues that need addressing in the disability space such as poor service provision or barriers to inclusion, collaborations/partnerships with the above would work well, especially considering these organisations have particular expertise and resources developed. A formal partnership would allow for information sharing and strategies to be developed to tackle entrenched problem areas whereby issues are addressed through a systematic concerted approach.

A forum/workshop of disability advocacy organisations can meet bi-monthly or quarterly to ensure consistency and information share.

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

**Answer:**

Some organisations receive NDAP funding for advocacy services as well as providing one or more disability support services. Such organisations are required to comply with the Disability Standards, and undergo annual audits and performance reviews to ensure compliance with the funding guidelines and meeting the outputs and/or outcomes. These funded organisations would be required to develop and implement conflict-of-interest policies and procedures and provide reports relating to any use of them.

In order to prevent any conflicts of interest, real or perceived, SCIA would recommend that any organisation that provides both advocacy and other provider services, be forthright and immediately explain this to any potential client requesting advocacy services. This information will allow the client to make an informed choice as to whether they wish to proceed with that organisation as their advocate. Furthermore we consider it highly unlikely that an individual or group will 'employ' an organisation's advocacy department to advocate against another service provided by the same organisation, once they have been made aware of this potential conflict of interest.

SCIA believes organisations that provide both advocacy and other services concurrently must be assessed on a case-by-case basis and must be compliant with the funding agreements, and client satisfaction. Also, organisations that provide advocacy as well as other disability support services can often obtain a better and faster outcome for the advocacy clients when the advocacy agency can draw on the resources and expertise of their other disability support services.

SCIA provides individual and systemic advocacy services for people with a spinal cord injury and other similar physical disabilities, their families and carers, with many successful outcomes through the both types of advocacy service. SCIA is aware of some people with disability preferred to use an advocacy agency that is part of an organisation with other disability support services because they have confidence that the advocacy agency is aware of the needs of people with disability, can provide a holistic approach and that services will be delivered in accordance with the Disability Standards.

There is also a case to be made for the positive role that specialist disability organisations offer in support of their representative cohort. SCIA has been providing an advocacy service for many years as well as covering other service areas including information, peer support, in-home after hours personal care/nursing support, accommodation and employment.

By way of example, SCIA's Policy and Advocacy Team employs four people working part-time to provide individual and systemic advocacy Monday-Friday. The team all have lived experience with spinal cord injury and disability which goes some way towards enhancing the advocacy work and provides a level of expertise; specialist knowledge is particularly important for certain cohorts of people such as spinal cord injury when providing advocacy support. It should also be stressed that even though SCIA was set up to advocate on behalf of people with spinal cord injury, the organisation supports all people with disability across its services.

More broadly, SCIA employs a significant number of people with spinal cord injury and similar disabilities across the organisation which influences and informs the work that it does, drawing on a large knowledge base that can only come through years of experience in navigating the disability service sector.

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

**Answer:**

To avoid gaps between the support provided by the NDIS and advocacy funded by the NDAP, SCIA supports the development and implementation of capacity building resources and training for people with disability that would empower them to self-advocate, in conjunction with providing them with details of the different types of advocacy and the different processes used to raise issues and resolve complaints.



SCIA has developed and delivered advocacy workshops and resources for people with disability to learn about advocacy and empower them to undertake self-advocacy if and/or when required. These workshops are delivered by people with disability, and although presented to groups in workshops, SCIA believes the content could be delivered using the various formats including live webcasts, video podcasts or modules viewed using a service like YouTube.

Providing advocacy and other capacity building training online provides the opportunity to reach all people with disability across Australia as long as they have access to computer equipment and the Internet.

People with disability, regardless whether they are eligible for the NDIS or not, will require access to a well-funded disability advocacy program that is independent of the NDIS. Without this, it would leave a significant number of people in a difficult and vulnerable position and without appropriate assistance to address issues they may encounter with their services and everyday life.

There continues to be gaps across all mainstream services in being fully open and inclusive to people with disability. It is also worth noting that older people who acquire a disability – after the age of 65 – have been completely locked out of the NDIS. They will have to negotiate the aged care sector in order to receive assistance, in a system that has been designed for the frail aged with little regard or understanding of high level disability. This has already caused major issues for people who are newly injured with a spinal cord injury over the age of 65 with little recourse for this cohort on exiting hospital and rehabilitation services. Advocacy support is and will continue to be vital for those aged over 65 with a disability especially with the population ageing; indeed, just over half (50.7 per cent) of Australians aged 65 and over identified themselves as having a with disability in 2015, compared to 1 in 8 (12.5 per cent) aged under 65, according to the 2015 Survey of Disability, Ageing and Carers released by the Australian Bureau of Statistics (ABS). With the aging population it has been forecast that by 2020 there will be more people living in Australia who are over the age of 65 than under the age of 20.

There is a good case to be made for allowing NDIS participants to use a small portion of their individual funding package through “capacity building” for self-advocacy. Advocacy organisation would be able to provide this support with the aim of empowering participants to pursue their own pathways for improving outcomes when problems arise.

Similarly, the Information, Linkages and Capacity Building (ILC) framework that is currently being developed should provide for block funded “advocacy” services along the individual and community capacity building streams, whether this be through peer support activities, or more broadly educating communities promoting the rights of people with disability.

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

**Answer:**

As mentioned in the answer for 4.2, block funded “advocacy” services should be provided with adequate funding to develop and implement programs for people with disability, their families and carers to educating them about the different types of advocacy as well as Australia’s human rights clause and legislations, and the different complaints resources and procedures that are available if required. This will enhance “capacity building”, and over time, may reduce the need (and related funding) for advocacy services.

**NOTE:** *The following background addresses what is needed to ensure the human rights of people with disability are protected but it is outside the NDIA authority.*

The Australian Government is a signatory to the UN Convention on the Rights of Persons with Disability, and the Australian Government is implementing the National Disability Strategy 2010-2020, of which the NDIS features as a key strategy to support people with disability to have more choice, flexibility and control of their services.

The Disability Discrimination Act (2002) was legislated to prevent or minimise disability discrimination as far as possible, however, any complaint accepted to be conciliated by the Australian Human Rights Commission (AHRC) that is unable to be resolved requires the complainant to either drop the complaint or pursue it in the Federal Magistrates Court. As the court system has a costs jurisdiction. This means the complainant may have to pay the costs of the respondents legal and court fees (even if the magistrate finds the respondent to have discriminated against the complainant). This is a major deterrent for complainants to pursue the complaint in court which results in their human rights not being protected.

The disability sector lobbied with submissions for the DDA review approximately three years ago seeking amendments to the role and authority of the AHRC Disability Discrimination Commissioner that would provide the Commissioner with the authority and resources to act on behalf of people with disability to pursue complaints in the court system, equal to a 'public prosecutor'.

**Questions:**

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

**Answer:**

If, as the discussion paper suggests, there are five organisations funded for legal advocacy and they are all in Victoria, then bearing in mind that legal frameworks vary widely across states and territories, it would appear that the way to address this would be to fund a legal advocacy service in each jurisdiction. Given that people with disability are overrepresented in this area, then it would be important to have available in all major centres an agency specialising in legal advocacy and advice for people with disability.

Again, thank you very much for providing SCIA with the opportunity to contribute to this review, and if the Department of Social Services requires further information and/or any of the above-mentioned content to be clarified, please do not hesitate to get in contact with the SCIA Policy and Advocacy Team.

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