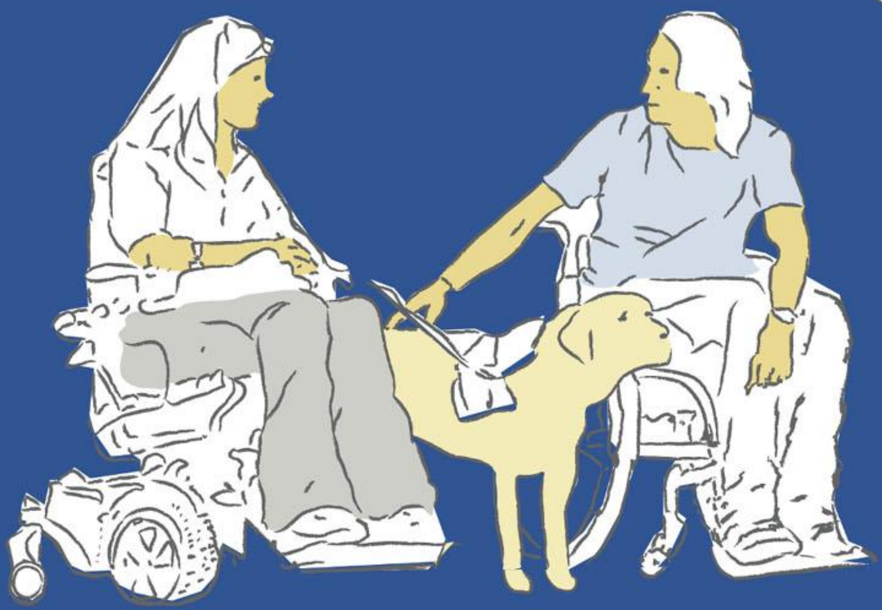
# National Advocacy Framework Review

SCIA Submission - Friday, July 31, 2015



scia
Spinal Cord Injuries Australia

scia
Spinal Cord Injuries Australia
doing whatever it takes after a spinal cord injury

# NDAF Submission

Friday, July 31, 2015

**Introduction**

Thank you for the opportunity to provide feedback to the National Disability Advocacy Framework review. It is timely that this review is being undertaken as there has been concern amongst advocates and stakeholders of the future of the funding of this important program.

Spinal Cord Injuries Australia (SCIA) commends the acknowledgement by the Department of Social Services (DSS) and the COAG Disability Reform Council for recognising the need to continue the recurrent ‘block’ funding for disability advocacy. It is hoped that this will pave the way for greater certainty in this space and allow the good work of the many organisations that are funded through the National Disability Advocacy Program (NDAP) to continue and most importantly, for the many people with disability that rely on the services they provide.

SCIA has been providing a dedicated advocacy service for a number of years with three staff members working (within our Policy and Advocacy Department) in the capacity of both individual and systemic advocacy work, as well as additional staff working in the individual advocacy arena, in regional areas. SCIA provides specialty knowledge in the area of Spinal Cord Injury and broader knowledge and experience across physical disability. It is important to highlight that SCIA have been in continuous operation since September 1967 and was started by people with an acquired spinal cord injury. SCIA continues today to have a large representative of people with spinal cord injury and similar physical disability working within the organisation. Not only does this create a vast knowledge base from which to draw from, but it also focuses the attention on pursuing positive outcomes for people with disability in the public space.

Due to the significant reform process currently underway across disability services and the ongoing rollout of the National Disability Insurance Scheme, it will be vital to maintain ongoing advocacy services by representative organisations, such as SCIA, to assist people with disability navigate what has traditionally been a complex web within disability service provision and its intersection with mainstream services.

SCIA strongly adheres to the notion that advocacy support must be free from any conflict of interest.

1. **Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?**

SCIA believes the current Framework encompasses its vision of advocacy, however, as the NDIS moves from a trial phase to a fully-fledged national program, the need for advocacy services will inevitably increase for various reasons, including more people with disability having access to more funding and new organisations entering the disability service sector. Therefore it will be paramount to increase current funding in this area to provide advocacy in a timely manner and to draw on the specialist knowledge already on offer.

It is worth highlighting that as the NDIS rolls out across the country, there will be many people with disability who will not be eligible for the NDIS. The need for advocacy services to assist this cohort – likely to represent a significant number of people – will continue as they negotiate the mainstream and community based service sector to find services to suit their needs; it is also likely that this will be a complex process and SCIA believes that local area coordination alone will not provide all the answers and be able to resolve the issues. Disability advocates in this space will be important in this domain and also in filling any void.

For people who will be eligible for NDIS services, and especially for many people with complex needs, it will still represent a confusing and complex system as they either transition from a state based service model across to the NDIS, or are receiving disability services for the first time. Either way it represents a significant challenge to understand procedures under a new service model; the early interactions with NDIA staff as services are discussed and negotiated during plan development will throw up many questions for new NDIS participants (and NDIA staff, if they not trained in a specific disability such as SCI). Being able to draw on the services of experienced advocates to assist with advice and referral will help this process.

It is worth noting that for many people entering into the NDIS, they will not have ever been previously asked about their goals and aspirations and how to go about developing a plan that reflects this. Traditional disability service models worked purely on assistance with personal care needs and had none of the flexibility that is available under the NDIS model. Having family members and significant others available on hand, as well as the right to an advocate, will help facilitate this process and ensure that the right level of supports are included in an individual's plan.

2. **Are the principles of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?**

SCIA believes the principles of the Framework are appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS. However, SCIA also believes the principles should ensure people with

disability are able to learn and develop by making mistakes, and the NDIS should provide the opportunity to enable those with a disability to have the "dignity of risk" which comes with individualised funding, offering flexibility and choice of obtaining services and supports. Obviously, such risks should be taken within specific "safeguards" to minimise any potential personal and/or financial negative impact to the NDIS. Providing the dignity of risk should also assist with the capacity building of people with disability, which would also foster self-confidence and increase the ability to self-advocate and develop leadership.

The first consideration is the changing funding model with people with disability being funded directly under the NDIS. But NDIS participants cannot be expected to set a portion of their funding to be identified in a plan to cover advocacy with an expectation that it may be needed at some point down the track. This is unrealistic and unworkable – people with disability cannot anticipate when problems are likely to arise and need to call an advocacy service for assistance. Therefore, it was encouraging to see the recommendation by the Productivity Commission for advocacy to continue to be funded outside of the NDIS, and SCIA believes it is vital the DSS through the NDAP recognises this dynamic and maintains adequate funding to cover advocacy services.

As mentioned in the introduction, there will be many people with disability that will not be in receipt of support packages or eligible for the NDIS; therefore the importance of advocacy is paramount to address service system shortfalls across mainstream services. Indeed, disability advocates play a vital role in terms of educating mainstream services and the community in general on the rights of people with disability and highlighting the barriers to social inclusion. Many people with disability do not have the skill or capacity to advocate on their own behalf – advocates play a role in raising awareness in government services and the community about people's rights and the need for equitable services and accessible facilities.

### 3. Are the outcomes of the Framework still relevant or should different ones be included? If so, what should be included?

A future market of disability support services will need to have robust accountability and advocacy will be important to this process for ongoing social inclusion. Representative organisations and advocates will continue to assist with design and review of programs to ensure that the policies and procedures are adequate and fully inclusive; this is not just about service delivery, but having mechanisms in place for consultation and feedback by service users – direct participation and representation on service delivery. This goes to the heart of what choice, flexibility and control means for people with disability.

Outcomes can be best achieved for people with disability through information sharing and providing avenues for this; disability advocates facilitate this. They help build capacity in

individuals and assist in making sensible choices by providing reliable consumer information, advice and referral as well as making information accessible.

People with disability are often marginalised and isolated either in their homes or inappropriately housed in institutions and many young people with disability are forced to live in aged care facilities. Coupled with this, many people with disability do not have a network of supports such as family and friends. This leaves people highly vulnerable. If problems arise such as abuse, the person with disability can feel like they have nowhere to seek help and it is more than likely that they do not know what their rights are. Disability advocates provide a support option for many people in this situation. Indeed, a recent Victorian Ombudsman's report (*Reporting and Investigation of Allegations of Abuse in the Disability Sector: Phase 1 – the Effectiveness of Statutory Oversight*, June 2015) bears this out and highlights the importance of advocacy in this space. Apart from the need of a single robust oversight mechanism, the report states *"there is a critical role for advocates to assist people with disability; however, there is limited appreciation of the importance of this role, manifest in its modest funding …"* Also, one of its recommendations is to undertake an assessment of advocacy needs of people with disability, and to ensure they have access to advocates to assist with allegations of abuse.

The Australian Senate inquiry (*Adequacy of Existing Residential Care Arrangements Available for Young People with Severe Physical, Mental or Intellectual Disabilities in Australia*) raised the importance of having advocates on-hand and assigned to young people in residential aged care and those at risk of entering into aged care facilities to help this cohort by providing information and assistance to navigate support options. Recommendation 9 of the report states the following:

> *The committee recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas:*
>
> - *assign an advocate to all young people living in residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person;*
> - *assign an advocate to all young people at risk of entering residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person. The advocate should be made available as early as possible after diagnosis of an illness or disability and be assigned before any placement commences.*

It should be noted that people with disability in this type of environment are usually not aware of programs they would be eligible for, let alone knowing what their rights are to pursue any grievances. The details above stress the role that disability advocates play across the entire spectrum of disability service provision and its intersection with aged care and

mainstream services. For this reason, people become reliant on these advocacy services, often because there has been no alternative. Without further assistance from advocates, it is more than likely they would be left out of the broad sweep of government policy and program reforms underway to improve the lives of people with disability. Many more people with disability, due to not being eligible for the NDIS, will fall outside the jurisdictional reach of the NDIS so it is imperative that they have access to quality and appropriately funded advocacy services.

### 4. Are the outputs of the Framework still relevant or should different outputs be included?

The three SCIA advocacy team members and their regional colleagues all have many years of lived experience of spinal cord injury and physical disability that informs the work that we do and enhances the advocacy service we provide. SCIA fields many calls asking for assistance from people with spinal cord injury and other similar physical disabilities. SCIA has a long proud history of supporting people with spinal cord injury and similar physical disability to achieve positive outcomes in their lives and removing barriers. The expertise that exists within SCIA provides a valuable service to people living in the community and those newly injured within a hospital setting or undergoing rehabilitation. At a systemic level, SCIA Advocacy Service provides submissions and attends public hearings to government inquiries, regularly communicates with local, state and federal ministers and government departments and agencies to highlight policy gaps as they affect people with disability. SCIA has developed a good reputation in this space for providing valuable information; members of the advocacy team are on government and non-government advisory committees that provides the opportunity to raise issues to remove barriers which leads to positive systemic outcomes and changes in how services interact with people with disability.

It is worth emphasising the role that specialist services offer in advocacy to people with disability and the community with their extensive knowledge base, without which would leave an enormous void and not be as effective. It is for this reason that the outputs in the framework should clearly define the need for organisations that provide advocacy to particular groups of people with disability.

### 5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?

With the current reform process in disability service provision with the rollout of the NDIS and the various legislation changes at a state, territory and federal level that will also alter how mainstream services will be provided to people with disability to make them more inclusive, it is clear that advocacy will play an important role in ensuring that services are accessible and provided on an equitable basis. Advocates will also play a vital role in a future

disability service marketplace by providing accountability and helping to shape and pursue ongoing social inclusion. For the many people with disability that will not be eligible for NDIS services, it will be just as crucial for the government to fund and maintain viable advocacy services to address service issues across mainstream and community services.

**6. Do you have any other comments, thoughts or ideas about the Framework?**

SCIA would like to acknowledge that the Framework is a well-rounded document that is relevant to the current and future disability environment in consideration of the rolling out of the NDIS which will provide individualised funding options for people with disability providing more choice, flexibility and control. However, it is an unfortunate fact of life that people with disability, their family and carers will continue to encounter barriers and be treated differently and with inequity to the rest of the general community from time to time, and regardless of the best intentions of advocates and advocacy services, it can be difficult, if not impossible, to remove or minimise barriers including direct and indirect discrimination.

The Disability Discrimination Act (DDA) 1992 does provide the opportunity for people with disability, their family and carers to pursue a complaint through the Australian Human Rights Commission (AHRC) in the event that a complaint against a person, business or organisation cannot be resolved quickly and amicably. The AHRC is not a Chapter 3 Court and if it is unable to conciliate the complaint fully or partially to the satisfaction of the complainant, the complainant has to decide whether to drop the complaint or pursue it in the court system. Unfortunately, there is a cost implication when a complainant lodges the complaint through the court system, and this is a major disincentive for people with disability who wish to seek a resolution through the courts, as it might result in costs being awarded against the complainant even if the complaint is proven; Particularly if the respondent is successful with a claim of unjustifiable hardship.

Although this above-mentioned issue might be outside of the Disability Advocacy Program Review process, SCIA believes it needs to be highlighted as it is a potential outcome when advocacy is unable to resolve a complaint. SCIA would like to advocate that the Department of Social Services (DSS) liaise with the Attorney Generals Department to seek amendments to the DDA to provide the availability of a fully funded disability "prosecutor" to act on behalf of people with disability, that is the similar to a Crown prosecutor in criminal matters.