### **About this Submission and its Authors**

Sector Support Development Network (herein known as 'SSDN') is a not-for-profit forum consisting of regional community development workers, training services and multicultural access workers formerly funded under the Home and Community Care (HACC) Program. They are now assisting services funded through the Commonwealth Home Supports Programme (CHSP) and the NSW Community Care Supports Program (CCSP) through aged care reforms [68% of SSDN members' funding] and transitioning disability supports to the NDIS [32%], respectively. Members are sector support workers with the following titles:

- Sector Support and Development Officer (SSDO)
- Aboriginal Sector Support and Development Officer (ASSDO)
- Multicultural Access Project Officer (MAP)
- Sector Support Development and Training Service (SSDTS)

These sector support workers are auspiced by a range of organisations, including regional and state peaks, community development organisations, local government and non-government organisations. Some have held this funding for thirty years, with workers in place for five, ten and occasionally more years. They have built networks and trust in their communities, where they are well-known and respected for their knowledge and the strength and quality of their work for, and with, providers and funders, promoting quality services for frail older people, people with disabilities and carers. Throughout their history, SSDN members, individually and as a group, have also provided a collective view on issues affecting the sector to the government bodies to all major projects and policy reviews. Currently, SSDN members are working with local service providers on readiness for, and at different stages of transition to, the NDIS.

SSDN members work together to identify systemic issues which impact upon the effectiveness of CHSP/CCSP to address access and equity issues and to contribute to change management processes, including dissemination of best practice policy and service models, and act as a reference point for government and other industry stakeholders. Similarly, they have been able to support CHSP/CCSP funded services to build capacity in transitioning to the NDIS, through innovative workshops and training, discussions at forums and dissemination of resources.

This response is a part of SSDN's efforts to articulate the role of community development in supporting and growing the community care supports sector for older people, people with disability and carers.

SSDN is in full support of the vision for a reformed National Disability Advocacy Program (NDAP) 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.

### Recommendations

- 1. That people with disability be actively involved in co-design of the new NDAP.
- 2. That the Australian Government undertakes to resource a network of advocacy services that are accessible to all people with disability, regardless of whether they are funded by the NDIS.
- 3. That the Australian Government undertakes to resource advocacy services to at least the levels of funding currently allocated through combined State and Commonwealth programs.
- 4. That NDAP includes a range of advocacy services to reflect the needs of the disability community.
- 5. That NDAP reflects a focus on quality, safeguarding and the professional status of formal advocacy.

# **Questions in the Discussion Paper**

## 1. Models of advocacy

# 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?

## The Need for Advocacy Services

The *United Nations Convention on the Rights of Persons with Disabilities* (the Convention) was a landmark document elucidating human rights of persons with disability. As a signature nation to the Convention<sup>1</sup>, Australia is required to report on measures taken to give effect to its obligations under the Convention<sup>2</sup>. Disability Advocacy is the activity of putting into practice the rights proclaimed by the Convention such as:

- Article 9 Accessibility
- Article 10 Right to life
- Article 11 Situations of risk and humanitarian emergencies
- Article 12 Equal recognition before the law
- Article 13 Access to justice
- Article 14 Liberty and security of the person
- Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Article 16 Freedom from exploitation, violence and abuse
- Article 17 Protecting the integrity of the person
- Article 18 Liberty of movement and nationality
- Article 19 Living independently and being included in the community
- Article 20 Personal mobility
- Article 21 Freedom of expression and opinion, and access to information
- Article 22 Respect for privacy
- Article 23 Respect for home and the family
- Article 24 Education
- Article 25 Health
- Article 26 Habilitation and rehabilitation
- Article 27 Work and employment
- Article 28 Adequate standard of living and social protection
- Article 29 Participation in political and public life
  - Article 30 Participation in cultural life, recreation, leisure and sport

Therefore, advocacy needs to be accessible for all individuals with disability, regardless of whether or not they are deemed eligible for funded supports under the NDIS. This ensures that people with disability are able to access and interact with members of the community beyond funded support services. NDAP must be reshaped around specific long-standing priority areas and issues coming from the new NDIS systems, such as:

- Guardianship
- Education
- Health
- Criminal Justice
- Deinstitutionalisation
- Sexuality
- People with multiple disabilities
- Any other advocacy issue stemming from the Convention

However, these are broad categories and in no way are they intended to restrict a person with disability from accessing advocacy supports for support around issues important to them which may not be listed here.

<sup>&</sup>lt;sup>1</sup> List of Signatory States and Regional Integration Organizations <a href="http://www.un.org/esa/socdev/enable/conventionsign.htm">http://www.un.org/esa/socdev/enable/conventionsign.htm</a>

<sup>&</sup>lt;sup>2</sup> Guidelines on treaty-specific document to be submitted by states parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities, Committee on the Rights of Persons with Disabilities Second session Geneva, 19–23 October 2009 <a href="http://www2.ohchr.org/SPdocs/CRPD/CRPD-C-2-3.doc">http://www2.ohchr.org/SPdocs/CRPD/CRPD-C-2-3.doc</a>

## **Current Spending on Disability Advocacy**

Advocacy spending on disability is not consistent across Australia with numerous state programs supporting the National Disability Advocacy Programme (NDAP). For example, the Victorian State Government funds twenty four organisations for advocacy; \$3.21 million for individual advocacy and \$1.59 million for systemic advocacy<sup>3</sup>. The NSW Government invests approximately \$10.25 million per year on advocacy and information provision.

In moving forward, the Australian Government needs to analyse current state disability advocacy programs and consider how to best include such supports in the NDAP. The NDIS presents a fundamental shift in providing supports and facilitating greater social access for people with disability. In this process, people with disability are highly likely to encounter barriers which may be addressed through various type of advocacy. Throughout this response, SSDN has discussed considered views as to how to best arrange disability advocacy services in order to meet the new and growing needs created by individualised funding.

As the number of people with disability accessing funded supports under the NDIS increases, disability advocacy resources must also be grown proportionately to the number of Participants

# **Specialisation of Advocacy**

Advocacy must be wide in scope to respond appropriately to a range of issues affecting diverse people. SSDN members believe that different approaches require different levels of specialised training and understanding, and the national disability advocacy program should fund organisations who specialise in specific areas, such as:

- Acquired Brain Injury
- Spinal Cord Injuries
- Autism
- Physical Disability
- Intellectual Disability

SSDN would also like to clarify that 'decision support' as a funded support in person's NDIS support package is not the same as individual advocacy. An advocate represents the needs, views and aspirations of a person with disability with respect to their rights; decision supports described in the NDIS Price Guide4 relate to funded supports only:

Support Item	Support Item Ref No.	Description
Assistance with decision making, daily planning, budgeting	15_035_07_1_3	Provision of time limited support to assist a person to develop and maintain daily budget, including assisting in planning purchases.

### **Education and Qualifications for Disability Advocates**

The NDIS space will be very different and more complex in which to advocate. Many advocacy issues over the years were concerned with access to services and problems with service delivery and now there are more providers registering to be a part of the Scheme. In addition, community inclusion, managing care and access to services under the NDIS involve new players, such as Local Area Coordinators and Merits Review Officers and services under the ILC Framework.

SSDN recommend developing the NDAP around the issues highlighted above and ensure this is supported by a National training program. It is important that people with disability and the NDAP services are involved in the design, as the NDIS has absorbed some advocacy and capacity building functions.

<sup>&</sup>lt;sup>3</sup> Reporting and investigation of allegations of abuse in the disability sector: Phase 1 – the effectiveness of statutory oversight June 2015, p21 https://www.ombudsman.vic.gov.au/getattachment/c6499f78-0eec-4e4a-8e94e4cd716a64f8//publications/parliamentary-reports/reporting-and-investigation-of-allegations-of-abus.aspx

<sup>4</sup> http://www.ndis.gov.au/providers/pricing-and-payment

## Service Delivery and Advocacy Separated

People with disability encounter environmental, structural and altitudinal barriers which, over time, can impact negatively on an individual's autonomy and capacity for advocating on their own behalf. Those individuals who require support to continue living independently are reliant on the service providers and their friends and family. This vulnerability leaves individuals open to mistreatment.

High quality and effective disability advocacy services require dedicated, highly skilled and professional staff. In order to avoid any potential conflict of interest, it is best to separate out advocacy functions to an independent third party. In our experience, people with disability would be cautious in dealing with an advocate from a particular direct service organisation due to:

- that auspice organisation's reputation in that local community, and
- the potential conflict of interest for an advocate auspiced by a direct care service provider.

# **Systemic Advocacy**

NSW funded services under the NSW Information and Advocacy Program are part of a network of support services for people with disability in NSW. This funding program encompasses seed funding for representative organisations who advocate on systemic issues, as well as information services such as IDEAS NSW. The peaks who receive this funding for Statewide advocacy are listed at <a href="https://www.adhc.nsw.gov.au/">https://www.adhc.nsw.gov.au/</a> data/assets/file/0016/234250/Advocacy Information Print Disability.pdf: Better Hearing Australia; Drug and Alcohol Multicultural Education Centre (DAMEC); Intellectual Disability Rights Service NSW; Multicultural Disability Advocacy Association of NSW; NSW Council for Intellectual Disability; Parents of Deaf Children; Spinal Cord Injuries Australia; Stroke Recovery Association NSW; The Deaf Society of NSW. There are also local regional services.

NSW Government is redirecting funding into the NDIS from 2018. These services seem to sit somewhere between the NDIS Information, Linkages and Capacity Building component of NDIS as well as NDAP, but SSDN is concerned that their vital work will not be acknowledged under a National allocation of funding.

#### Service Model

The length of time for advocacy supports services varies greatly depending on the complexities of the case and the person's communication skills. The best way to fund advocacy services is to de-couple them from the person's support needs, as we do not want to put people with disability in a situation where they are forced to forgo services in order to be able to pay for advocacy. To ensure immediate availability of services, we recommend continued block-funding to advocacy services across the continuum of disability advocacy, from independent information to assist self-advocacy, through the provision of individualised advocacy brokerage, to facilitated group advocacy, individual advocacy and systemic advocacy.

The service model needs to be flexible enough to be able to deliver each of the following types of advocacy we have identified; please see below.

Advocacy Type	Current NDAF Stream	Nature of Delivery	Resourcing Needed	Suggested NDAF Stream
Self Advocacy & Peer Advocacy	Individual Advocacy	Informal: By person with disability	Information, capacity building etc	Community Advocacy Supports
Family Advocacy & Parent Advocacy	Individual Advocacy	Informal: By carer/s	Information, capacity building etc	Community Advocacy Supports
Group Advocacy	Individual Advocacy	Informal: By person/s with disability or carer/s	Information, capacity building etc	Community Advocacy Supports

Citizen	Individual	Informal: By	Information,	Community Advocacy
Advocacy	Advocacy	volunteer	capacity building	Supports
			etc	
Legal Advocacy	Individual	Formal: By paid	Wages, service	Systemic Advocacy
	Advocacy	worker	costs etc	
Systems	Systemic	Formal: By paid	Wages, service	Systemic Advocacy
Advocacy	Advocacy	worker	costs etc	
[education]	Disability	Formal: By paid	Wages, service	Community Advocacy
	Advocacy	worker	costs etc	Supports
[Professional]		Formal: By paid	Wages, service	Formal Individual
Individual		worker	costs etc	Advocacy
Advocacy				

#### 1.2 What are the drawbacks?

Hugh quality professional disability advocacy services are resource intensive as they require highly skilled staff to work face-to-face with individuals and local communities in order to place based develop solutions. Initial investment is likely to be significant, but as programs get under way and issues of barriers to social participations of people with disability are addressed by a workforce of dedicated individuals, these costs are likely to fall over time.

# 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?

# 'Hub-and-Spokes' Model

SSDN are in favour of a 'hub-and-spokes' model featuring continuation of funding for specialised disability advocacy agencies to provide highly tailored, expert advocacy services for people with disability across the country. Under this model, 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.

# 2. Improving access to advocacy supports [practical strategies to remove barriers]

Rights and advocacy are not well understood by people with disability. SSDN notes Article 8 of the Convention, which

"establishes the obligation of States Parties to conduct effective awareness raising policies to promote a positive image of persons with disabilities. The report should contain information on the measures taken to raise awareness of persons with disabilities, to foster respect for their rights and dignity, their capabilities and contributions, and to combat stereotypes, and prejudices against them"

SSDN therefore recommends a multi-pronged approach, including:

- Community Campaign around what behaviours are acceptable and not acceptable, how to stay safe, who can help and how they can help; similar to the Living Life My Way Ambassadors and Champions and the Don't Dis My Ability.
- Education campaign for people with disability and the wider community about attitudinal disability and social inclusion. Organisations such as Every Australian Counts and the NSW Consumer Development Fund - My Choice Matters are doing similar work now raising awareness of the NDIS. Their mandate may be extended to include discussions about rights, abuse and advocacy.
- NDIA to provide information to each Participant about advocacy services through either the External Merits Review Process or more widely through the NDAP.
- Special focus on people with multiple disabilities and people living in institutions<sup>5</sup>.

<sup>&</sup>lt;sup>5</sup> see SHUT OUT: The Experience of People with Disabilities and their Families in Australia

## 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?

In facilitating access for Aboriginal and Torres Strait Islander communities, people with disability from culturally and linguistically diverse communities and people with disability in rural, regional and remote locations SSDN recommends:

- consultation with local communities around access to disability advocacy in that local community, in
  order to ensure that services are targeting the appropriate population around specific advocacy issues
  which would form part of a larger Regional Advocacy Engagement Strategy; and roll-out an education
  program about disability rights and advocacy tailored to the Aboriginal and Torres Strait islander
  community and further versions in key community languages. Including practical resources in key
  community languages and a version tailored for the Aboriginal and Torres Strait islander community.
- Making informed decision about one's life a basic human right. Therefore, we recommend access to translating and interpreting services for both clients and service providers at no cost to the person with disability or the service provider.

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

SSDN is also in full agreement with the NSW Council for Social Services (NCOSS), when they speak about engaging with Aboriginal Torres Strait Islander and Aboriginal Communities around the NDIS. In their report *Plan first, don't 'retrofit': delivering on the promise of the NDIS for Aboriginal and CALD people in NSW*, they provide excellent suggestions:

- Be aware that the workforce to deliver effective community engagement with Aboriginal and CALD communities may need time to scale up - so early engagement with Aboriginal and CALD community organisations and realistic processes of codesign will be key to delivering against the recommendations noted above.
- Employ Aboriginal and CALD staff at senior levels within organisations, including managers of Local Area Coordinators, and not just as frontline workers, to ensure accountability for both expenditure and outcomes at an organisational level.
- Ensure that organisations working in the sector can demonstrate high-level commitments to genuine inclusion for Aboriginal and Torres Strait Islander peoples, as well as CALD people.

### 3. Improving the advocacy evidence base and coordination on systemic issues [more than MDS]

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

- 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?

In the previous consultation round of the NDAP Review, which reviewed the *NDA Framework*, SSDN members contributed to a submission by NSW Community Care Issues Forum, which dealt with these questions, specifically in regard to oversight and complaints. Seeking consistency across the current complexity of the legislative arrangements that lead to different levels of protection of people with a disability, and assistance available, across jurisdictions, the CCIF called for:

- Establishment of a National Disability Safeguarding Framework based on the powers currently exercised by the NSW Ombudsman under the *Disability Inclusion Act 2014* (NSW), which introduced a system administered by the NSW Ombudsman for reporting and oversight of serious incidents involving people with disability in supported group accommodation. This provision needs to be further expanded to include, "a requirement for mandatory reporting of all complaints, allegations or incidents which could indicate abuse of a person with disability" regardless of whether or not the person lives in supported accommodation.<sup>6</sup>
- Strengthened powers to investigate *suspected mistreatment*, as the Public Guardian's powers are limited to issues relating to vulnerability and diminished capacity. If there are other concerns which do not meet this threshold, and there is no readily apparent evidence which would trigger an investigation, then the Public Guardian cannot investigate.<sup>7</sup>
- Extending the Official Community Visitors Scheme and the definition of visitable services defined in section 8 of the Community Services (Complaints, Reviews and Monitoring) Act 1993 to include any location where disability supports are being delivered, as under the NDIS more and more supports are delivered in-home or in the community.

The current NDAP service system is fragmented, with great variability in service availability and quality across the nation. The future NDAP should be based on the National Disability Advocacy Framework (NDAF) and state funded advocacy services, but first and foremost it needs to be an integrated system directly informed by the voice, choice and control of people with disability, in keeping with Principle (e) of the current NDAF:

"Disability advocacy ensures that views represented meet the individual preferences, goals and needs of people with disability"8

#### And Outcome G:

"People with disability are actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them"

Just as NDIS is about individuals experiencing the lives they want, so should the NDAP provide the nature of advocacy supports demanded by people with disability, including:

- models of advocacy;
- mix of formal [funded] advocacy and informal [unfunded] peer support and self-advocacy;
- geographic spread and availability; and
- range of providers.

# 4. The interface with the NDIS and addressing conflict of interest [NDAP provider + NDIS/ILC provider]

- 4.1 What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?
- 4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?
- 4.3 What policies and strategies do we need to protect the rights of people with disability?

[see models outlined in Question 1]

- 5. Understanding and improving access to justice
- 5.1 What forms of legal review and representation do people with disability need most?
- 5.2 What barriers prevent people with disability from accessing justice?
- 5.3 What models of legal advocacy are most effective?

<sup>&</sup>lt;sup>6</sup> Reporting and investigation of allegations of abuse in the disability sector, p83

<sup>&</sup>lt;sup>7</sup> Reporting and investigation of allegations of abuse in the disability sector, p69

<sup>8</sup> Section 10 at <a href="https://www.dss.gov.au/sites/default/files/documents/11">https://www.dss.gov.au/sites/default/files/documents/11</a> 2014/attachment a.2 - <a href="national\_disability\_advocacy\_framework.pdf">national\_disability\_advocacy\_framework.pdf</a>

<sup>&</sup>lt;sup>9</sup> Section 12 at https://www.dss.gov.au/sites/default/files/documents/11\_2014/attachment\_a.2\_national disability advocacy framework.pdf

SSDN supports the Disability Justice Project in NSW at <a href="http://www.disabilityjustice.edu.au/contact-us">http://www.disabilityjustice.edu.au/contact-us</a>. The cluster of Justice Services in NSW utilises a Disability Advisory Council, which includes a member of SSDN. Several individual services are also responding to the NDAP Review, as they make wide use of NDAP services for people with disability.