

Australian Cross Disability Alliance



Submission

Department of Social Services

Review of the National Disability Advocacy Framework

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1. Introduction

The Australian Cross Disability Alliance (ACDA) provides this submission in response to the Department of Social Services (DSS) *Discussion Paper - Review of National Disability Advocacy Framework* (the Discussion Paper).

ACDA is a coalition of Disabled Peoples Organisations (DPOs), which are organisations run by and for people with disability.¹ ACDA promotes and seeks to advance the human rights and freedoms of all people with disability in Australia. Our work is grounded in a normative human rights framework that recognises the United Nations human rights conventions and related mechanisms as fundamental tools for advancing the rights of people with disability in Australia and internationally.

ACDA is the recognised nexus between government, people with disability and other stakeholders.

We thank DSS for the opportunity to comment on the Discussion Paper.

2. Overarching Comments and Recommendations

The ACDA fully supports the ongoing programmatic structural arrangements for the National Disability Advocacy Program (NDAP). This includes the independence of NDAP from the National Disability Insurance Scheme (NDIS). It is essential that independent advocacy is viewed as a critical component of achieving the outcomes for both the NDIS and the National Disability Strategy (NDS).

We believe **NDAP is strengthened by all models of independent advocacy, including individual advocacy, self advocacy, legal advocacy, systemic advocacy, family advocacy and citizen advocacy.**² We strongly support every model of advocacy, including systemic advocacy being encapsulated within the NDAP. Each model of advocacy delivers important outcomes for people with disability.

The ACDA recognises the mutually supportive and beneficial roles played by DPOs and independent advocacy agencies. DPOs undertake representation of people with disability as well as self-advocacy and systemic advocacy, and some DPOs are funded under the NDAP to provide individual and other forms of advocacy.

In addition to the following comments, **ACDA supports the conclusions and recommendations of the Final Report, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program* prepared for the Department of Families, Housing, Community Services and**

¹ ACDA comprises First People's Disability Network (FPDN), National Ethnic Disability Alliance (NEDA), People with Disability Australia (PWDA) and Women With Disabilities Australia (WWDA).

² These forms of advocacy are outlined on the DSS website at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap>

Indigenous Affairs in 2009.³

In this section, the ACDA would like to make the following key overarching comments and recommendations, before commenting on the specific questions outlined in the Discussion Paper.

2.1 Human Rights Framework

ACDA welcomes the commitment that the National Disability Advocacy Framework (NDAF) will continue to be guided by the principles and priorities of the Convention on the Rights of Persons with Disabilities (CRPD) and related human rights instruments. We also welcome that the NDAF will be designed and delivered with the practical commitment to improving disability advocacy to ensure the consistent achievement of human rights outcomes for all people with disability.

Embedding human rights in the NDAF provides the critical, common link to the human rights principles and objectives embedded in the NDS and the NDIS. The NDS is the strategy agreed by all Australian governments to implement and report to the United Nations (UN) against progress in achieving the CRPD.⁴ The NDS adopts the principles within the CRPD⁵ and aligns the NDS six policy areas to the CRPD.⁶ The objects and principles in Part 2 of the NDIS Act state that the Act gives effect to Australia's obligations under the CRPD and certain obligations under other human rights treaties. In other words, along with the NDS and the NDIS, the NDAP is a critical, interconnected component of progressing the human rights of people with disability, and supporting Australia's international human rights obligations.

Underpinned by human rights, the NDAF enables independent advocacy to be conducted in an agreed framework that is consistent with the NDIS and the NDS. This is critical to ensure that independent advocacy is not driven, or perceived to be driven by ideology, biased positions or other self-interests, but by uniform, nationally and internationally agreed human rights principles.

2.2 Investment in the National Disability Advocacy Program

NDAP remains critically under resourced for it to achieve its objectives and the desired human rights outcomes for all people with disability in Australia. With this in mind, we make the following points:

- **Significant investment to all NDAP models of advocacy is required to deliver either equitable access or representation of issues for people with disability.**
- **Investment in all models of independent advocacy needs to significantly increase to match increased advocacy demand in the NDIS environment.** The NDIS is a major reform that has brought significant change to the lives of people with disability and increased demand for advocacy support, for example:

³ Available at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program>

⁴ Council of Australian Governments, *National Disability Strategy 2010-2020*, Commonwealth of Australia 2011, pp. 16-17

⁵ Ibid p. 22

⁶ Ibid p. 17

- NDIS participants seek assistance to find information about the NDIS; to understand the opportunities and challenges of the new system; develop their plans; receive decision making supports; liaise with the NDIA, and existing and potential service providers; choose between services and supports; manage their plan; employ support workers; and navigate complaint handling processes. Independent advocates play a key role in assisting with these issues, but to do so requires the acquisition of new and constantly changing knowledge and expertise in myriad areas, on top of providing advocacy support to people with disability who are not eligible for the NDIS or whose advocacy requirements are outside of the parameters of the NDIS' remit.
 - Independent advocacy agencies provide assistance, advice and information to government agencies, families and service providers to facilitate case management and other interactions for people with disability. The transition to the NDIS is rapidly changing the structure of disability service provision and this places increased pressure on advocates to provide feedback and practical advice to service systems as to how these changes are effecting people with disability and how to respond.
 - In the changing disability service landscape advocates are often the only constant independent support for people with disability. Advocacy agencies are being increasingly called upon for assistance from people with disability, families, government and service providers. The impact and value of this role should not be underestimated or taken for granted.
 - Potential or actual NDIS participants will require advocacy support from advocacy agencies with specific local and regional knowledge of the evolving market for disability supports. Advocates based in local communities are best placed to provide this assistance to people with disability, but often advocacy is not readily available for many people with disability, particularly in rural, regional and remote areas.
- **Investment in all models of independent advocacy is critical to progress NDS outcomes.** For the NDIS to be successful, there must be parallel progress in achieving the outcomes in the six policy areas – inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; health and wellbeing.

People with disability, whether they are NDIS participants or not may require advocacy assistance at any time to address issues unrelated to the NDIS, such as finding supports for those over the NDIS eligibility age threshold, accessing inclusive education, making consumer complaints, finding appropriate, accessible housing, responding to violence and abuse, addressing employment discrimination, accessing the justice system or for many other issues.

NDIS participants and people with disability not eligible for the NDIS must have equal access to independent advocacy supports. It would be a perverse outcome if participation in the NDIS either prioritised or deprioritised a person's access to independent advocacy.

- **Culturally competent advocacy support requires significant investment for the success of the NDIS and the NDS.** It is already known that there are significant gaps in culturally

competent advocacy support for Aboriginal and Torres Strait Islander people with disability and people with disability from culturally and linguistically diverse (CaLD) and non-English speaking backgrounds (NESB). These gaps do not reflect the considerable need for advocacy support in the NDIS environment and in achieving NDS outcomes:

- People with disability from CaLD or NESB are considerably underrepresented within the disability service system.⁷ For example, when compared to Australians born in English speaking countries, Australian residents born in a non-English speaking country are 4 times less likely to receive accommodation support services, 2.5 times less likely to receive community support services, 2.5 times less likely to receive community access supports and 3 times less likely to receive respite services.⁸

CaLD people with disability also need significant advocacy support to access, transition into and appropriately navigate the NDIS. In 2014, only 4% of NDIS participants identified as being from a CaLD and/or NESB backgrounds.⁹ Taking into consideration that around 25% of people with disability are from CaLD backgrounds¹⁰, this means that CaLD people with disability are significantly underrepresented in the scheme.

- In addition to disability support needs, CaLD people with disability (and their families and carers) will also require advocacy support and/or education to enable them to appropriately navigate service systems they interact with in other aspects of their life such as for housing, employment, education, legal, migration and consumer-welfare related concerns. Aboriginal and Torres Strait Islander peoples with disability and their families are amongst the most seriously disadvantaged members of the Australian community, with figures indicating that the incidence of disability in Aboriginal and Torres Strait Islander communities is at least 50%.¹¹

To address the myriad forms of discrimination and disadvantage, as well as support access and culturally appropriate transition to the NDIS, **advocacy support that is owned and managed by Aboriginal and Torres Strait Islander peoples and communities should be developed and resourced.**

2.3 The provision of advocacy must remain independent.

Independence from service systems and disability support agencies is critical to ensuring that advocacy support is free from conflicts of interest and always puts the rights, will and preference of people with disability at the forefront.

In the NDIS context, it is critical that independent advocacy is not viewed as being superceded by

⁷ National Ethnic Disability Alliance (NEDA), 'Access to Disability Services for people for Non-English Speaking Backgrounds with Disability', 2013, <http://www.neda.org.au/index.php/reports/item/disability-services-utilisation> (accessed 6 July 2015).

⁸ Ibid.

⁹ National Disability Insurance Agency, 'NDIA Quarterly Report to COAG Disability Reform Council', 31 December 2014. At: <http://www.ndis.gov.au/document/754>

¹⁰ National Ethnic Disability Alliance, Datacube 2014, Available at: <http://www.neda.org.au/index.php/statistics/156-data-cubes>

¹¹ First Peoples Disability Network, <http://fpdn.org.au/>

NDIS roles, such as the roles played by NDIS planners and Local Area Coordinators (LACs). While these roles are important, and may include aspects of information provision, advice and service system linkages, this is not an independent advocacy role.

Independent advocacy, along with DPOs play an independent role in identifying disability and mainstream systemic risks and gaps, resolving complex situations for people with disability across multiple agencies and providing a voice for people with disability in decision-making processes including legislative, policy and program design, implementation and evaluation. Many of the failures of the disability and mainstream support systems that result in significant human rights violations are only brought to the attention of specialist and mainstream complaints and oversight bodies by DPOs and independent advocates, and independence from these systems is critical.

2.4 Investment in DPOs, independent advocacy and independent information by Commonwealth, State and Territory Governments.

The growth in demand for independent advocacy, independent information and representation is not being matched by increased investment at all levels of government. Some States and Territories are maintaining funding for a residual advocacy role, while others, such as NSW are discontinuing funding for all forms of independent advocacy and representation. The view is that these critical roles will become the responsibility of the Commonwealth in the NDIS environment.

It is highly likely that this situation will place additional strain on the existing, overburdened advocacy and DPO sector, create inequity in advocacy support between State and Territories, and the loss of local advocacy expertise for people with disability. It will also reduce the ability of all governments to seek essential advice and support in the implementation of the NDIS and the broader inclusion agenda outlined in the NDS.

Representation and independent advocacy must be equitably available to all people with disability regardless of the State or Territory in which they live. Investment, funding and resourcing for representation, independent advocacy and independent information needs to be available from both Commonwealth and State and Territory Governments. At a minimum, levels of funding must be equal to the current combined investment from the NDAP and the State or Territory Government.

2.5 Investment in DPOs and independent advocacy for critical and emerging roles in the NDIS.

- In response to the Consultation Paper for the NDIS Quality and Safeguarding Framework, a number of submissions noted the critical role that DPOs and independent advocacy agencies play in ensuring quality and safeguarding for people with disability. NDIS participants and those who are not NDIS eligible will need increasing support to navigate and adapt to the disability and mainstream service environment; governments will still need consultation mechanisms to develop and implement effective laws and policy; and independent voices will be needed to ensure that the market for disability supports grows in a way which promotes human rights.

No support systems are perfect, and DPOs and independent advocacy act as ‘early warning systems’ and ‘system savers’ to prevent and respond to limitations and failures for people with disability. **The fundamental role of DPOs and independent advocacy in NDIS quality and safeguarding must be recognised, enhanced and resourced.**

- In the development of Information, Linkages and Capacity Building (ILC) framework, it is critical to recognise that **DPOs and many advocacy agencies already undertake, and have significant expertise in functions, programs and activities that constitute ILC support.** For example:
 - Providing disability rights information, linkages and referral to inform people with disability about their rights and to connect them to relevant disability and mainstream supports;
 - Providing training to local councils, disability and mainstream service providers to build capacity to effectively design best practice service delivery and enhance inclusion of people with disability;
 - Providing advice and support to government and non-government service providers in the development of Disability Action Plans that eliminate disability discrimination and create accessible workplaces and customer service environments;
 - Self-advocacy capacity building through peer support activities and training programs;
 - Building and supporting local peer support groups of people with disability to share and learn from each other, such as the peer support activities of Disability Support Organisations (DSOs);
 - Providing training to people with disability, service providers, NDIA staff on specific issues, such as human rights, preventing and responding to violence and sexual assault, communication and supported decision-making;
 - Providing supported decision-making assistance and capacity building to people with disability, NDIA planners and service providers, including providing communication supports and developing supported decision-making tools and mechanisms;
 - Facilitating consultation and collaboration with people with disability to enable evaluation of the disability and mainstream support system, such as the recent Citizens’ Jury Scorecard Project.¹²

Investment in the existing expertise within the DPO and advocacy sector is more efficient than ‘reinventing the wheel’ for ILC support. This investment should also recognise that:

- People with disability are experts in their own lives, and DPOs are a rich resource: they have been consulting and collaborating with each other, sharing information and knowledge on good practice, providing capacity building and delivering training to peers, specialist and mainstream services for decades;
- Peer to peer capacity building, supported-decision making, information provision and

¹² <http://pwd.org.au/admin/ndis-citizens-jury-scorecard-project.html>

training maintains and develops relationships of trust, community and empowerment between people with disability;

- Independently developed and delivered training is not effected by existing relationship dynamics between people with disability and service providers or government agencies, and thus avoids potential conflicts of interest;
- DPOs and independent advocacy works from a human rights perspective that underpins the NDIS and the NDS.

3. Responses to Specific Questions

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

As outlined in section 2.1 in this submission, ACDA endorses a NDAF that is underpinned by the CRPD and related human rights instruments. The current framework strengthens disability advocacy in Australia by drawing on the CRPD as a guiding document. It is imperative that the NDAF remains firmly positioned within an international human rights framework and that this commitment is reflected in all NDAF principles, outcome and outputs.

However, changes will need to be considered to reflect the critical role of advocacy in relation to the NDIS Quality and Safeguarding Framework and the ILC framework, as discussed in section 2.5 in this submission. Given these frameworks are still being developed, it is difficult to propose specific changes in this submission. Nevertheless, it will be important that **there are references in the Principles, Outcomes and Outputs that focus on the roles of quality and safeguarding, capacity building, peer support, self-advocacy, training and supported-decision making.** While there is some reference to some of these roles, they are not all included and those that are could be strengthened in the context of the NDIS environment. These changes could be considered in consultation with DPOs and advocacy organisations during the finalisation of the frameworks.

Another key area for change is in the area of supported decision-making and legal capacity as articulated in Article 12 of CRPD. Currently, there are a number supported decision-making pilots, trials and projects being conducted in various jurisdictions across Australia in an effort to comply with the CRPD. In 2014, the Australian Law Reform Commission (ALRC) tabled in parliament the final report of its inquiry into barriers to equal recognition before the law and legal capacity for people with disability, *Equality, Capacity and Disability in Commonwealth Laws*. The report makes 55 recommendations for reform, and 5 of these recommendations relate specifically to the NDIS Act.¹³

With this in mind, it is important that the NDAF is reviewed to reflect the CRPD in this regard, as well as the four principles recommended in the ALRC report – the equal right to make decisions; support in decision-making; will, preferences and rights; and safeguards. **Terminology in the**

¹³ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (2014), Commonwealth of Australia, pp.129-157

principles, such as “preferences, goals and needs of people with disability” should reflect the terminology of CRPD – “will, preferences and rights of people with disability”.

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?

In addition to the comments made in response to question 1 above, each of the existing NDAF principles are listed below with issues highlighted and recommended changes indicated where relevant.

a. *Disability advocacy operates under relevant Commonwealth, State and Territory legislation and the principles of the United Nations Convention on the Rights of Persons with Disabilities and other relevant United Nations Rights Treaties, to protect and promote the legal and human rights of people with disability*

ACDA endorses this principle.

b. *Disability advocacy promotes the interests and wellbeing of people with disability and promotes their full and valued inclusion as contributing and participating members of the community*

ACDA endorses this principle.

c. *Disability advocacy seeks to influence positive systemic changes in legislation, policy and service practice and works towards promoting inclusive communities and awareness of disability issues*

ACDA endorses this principle, but would like to see stronger human rights language incorporated, such as including the phrase “works towards **progressing the rights of people with disability**, promoting inclusive communities and **raising** awareness of disability issues”.

Adding this phrase also reinforces the connection to the human rights framework that underpins the NDIS and the NDS.

d. *Disability advocacy promotes leadership and capacity building by people with disability*

ACDA endorses this principle.

e. *Disability advocacy ensures that views represented meet the individual preferences, goals and needs of people with disability*

In its current form, this principle is unclear and could imply that disability advocacy determines, on behalf of an individual, their preferences, goals and needs, rather than supports an individual to express their will and preference (see also discussion on supported decision-making under responses to question 1 above).

This principle is also confusing in that it could be directed at systemic advocacy, where the collective rights of people with disability are represented, or at individual advocacy where an advocate represents an individual's views to external parties. In terms of systemic advocacy and representation of views, the principle should focus on representing the views of people with disability in accordance with human rights. In terms of individual advocacy, the principle should focus on expressing the will, preferences and rights of the individual with disability.

f. Disability advocacy strengthens the capacity of people with disability to speak for themselves by actively supporting and encouraging self-advocacy

ACDA endorses this principle.

g. Disability advocacy recognises and respects the diversity of people with disability

The current wording of this principle is vague. It is unclear if the principle refers to diversity in the nature and type of disability, diversity of lived experience of disability, or diversity of other aspects of individuals' identities or all of these things.

Disability advocacy remains a critical mechanism in promoting, protecting and ensuring human rights of all people with disability. However, there are inequalities between population groups of people with disability in accessing and being appropriately supported by advocacy agencies.

Some population groups experience multiple and systemic disadvantage over and above those experienced by the broader population due to intersectional experiences of discrimination, prejudice, and systemic marginalisation. These populations can include Aboriginal and Torres Strait Islander people with disability, people with disability living in rural and remote locations, women and girls with disability, children and young people with disability, older people with disability, people with disability from culturally and linguistically diverse backgrounds, and people with disability who are lesbian, gay, bisexual, transgender, intersex and or sexuality or gender diverse.

The NDAF principles must be explicit about addressing the needs, issues and experiences of these population groups. In addition, this principle must be matched by statements under the Outcomes and Outputs, and by specific, achievable and measurable outcomes for disability advocacy providers.

While ACDA acknowledges that the NDAF principles are, by necessity, high level, this principle should be reworded to include specific references to these population groups. For example:

“Disability advocacy recognises and respects the diversity of people with disability, including the intersectional dimensions of this diversity related to age, gender, gender identity, intersex variations, sexuality, Indigenous status, ethnicity, cultural and linguistic background, and geographic location”.

h. Disability advocacy ensures that the rights of people with disability to privacy, dignity and confidentiality are recognised and upheld.

ACDA endorses this principle.

- i. *Disability advocacy will foster effective strategic alliances to develop capacity to identify and respond to the needs of people with disability.*

ACDA endorses this principle.

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

- a. *people with disability are accorded the rights and freedoms described in the United Nations Convention on the Rights of People with Disabilities and other relevant United Nations Rights Treaties*

ACDA endorses this outcome.

- b. *people with disability achieve economic participation and social inclusion*

While ACDA broadly endorses this outcome, it would be much stronger if it reflected the full range of civil, political, economic, social and cultural rights that are contained in the CRPD. For example:

“People with disability are able to participate in all aspects of the civil and political, economic, social and cultural life of our communities.”

- c. *people with disability enjoy choice, wellbeing and are supported to pursue their life goals*

This outcome could be stronger if it reflected more current language used in the NDIS. For example:

“people with disability enjoy choice and control over their wellbeing and the pursuit of their life goals”.

- d. *people with disability are able to make decisions that affect their lives, or where necessary are supported in making those decisions*

This outcome should be strengthened to become more consistent with the CRPD. For example:

“people with disability exercise their right to make decisions, are involved in all decision making processes that affect their lives, and receive the support they need to make those decisions”.

- e. *people with disability receive independent advocacy support that is free from conflict of interest*

ACDA endorses this outcome.

- f. *people with disability experiencing multiple disadvantage have their needs met*

The current wording of this outcome is vague. In the Glossary to the NDAF¹⁴, multiple disadvantage appears to mean disadvantage related to intersectional discrimination, such as that experienced by women and girls with disability or children and young people with disability. However, the word ‘education’ is also included which implies that particular barriers to participation creates multiple disadvantage.

In order to be clear and measurable, this outcome could include the words **“intersectional discrimination”**, and then a broader explanation could be provided in the Glossary. For example, the Glossary could explain multiple disadvantage as relating to people with disability who experience multiple layers of barriers within and between service systems or in their life, such as people entering and exiting the criminal justice system without housing, disability and other social support, no income and no family or other circles of support.

The Glossary could also explain intersectional discrimination as **“the specific discrimination that is the result of the intersection between disability and other characteristics, such as, but not limited to gender, age, ethnicity, cultural and linguistic background, Indigenous status, sexuality, gender identity, intersex variations , or geographic location”**.

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.

ACDA endorses this outcome.

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

a. Individual advocacy that is tailored to meet the individual needs of people with disability including a focus on the needs of people with disability experiencing multiple disadvantage

This output should be reworded to include the words, **‘intersectional discrimination’** in order to specifically identify population groups who experience multiple disadvantage and intersectional discrimination – see our response under Outcome f, question 3.

b. Disability advocacy that is informed by an evidence base and is provided in an accountable and transparent manner

The wording of this output could be strengthened to become more consistent with the guiding human rights framework. Suggested wording:

“Disability advocacy that is informed by an evidence base, is provided in an accountable and transparent manner, and is consistent with the CRPD and related human rights instruments”.

¹⁴ https://www.dss.gov.au/sites/default/files/documents/11_2014/attachment_a.2_-_national_disability_advocacy_framework.pdf

- c. *Disability advocacy that is planned and delivered in a coordinated manner and supports communication between disability advocacy support, disability services, mainstream services and governments*

This outcome should include reference to communication and building relationships with DPOs and peer support groups. For example:

“Disability advocacy that is planned and delivered in a coordinated manner and supports communication between disability advocacy support, disability services, peer support and DPOs, mainstream services and governments”.

- d. *Disability advocacy that promotes community education and awareness of disability issues and rights*

ACDA endorses this output.

- e. *Systemic advocacy that positively contributes to legislation, policy and practice that will support the agreed outcomes.*

ACDA endorses this output.

In addition, the NDAF should include an additional output that is consistent with the first NDAF Principle and Outcome. For example:

“Disability advocacy that is consistent with the United Nations Convention on the Rights of Persons with Disabilities and related human rights instruments”.

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

As discussed in section 2 of this submission, the current and future disability environment will increase the demand for independent advocacy. This increase in demand must be matched by an investment in all models in independent advocacy by all levels of government.

In addition, there are critical and emerging roles for independent advocacy and DPOs in the NDIS environment related to the Quality and Safeguarding Framework and the ILC framework. This is discussed in section 2.5 and section 3 under question 1 of this submission. The final frameworks are likely to influence changes in the NDAF that may be required to reflect these roles.

The NDAF could be further strengthened by a requirement for robust, transparent and comprehensive disaggregated data gathering and analysis strategies that directly measure outcomes against the CPRD and related human rights instruments.

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

ACDA thanks the DSS for the opportunity to provide this submission.