



Submission

**Department of Social Services (DSS)
Review of the National Disability Advocacy Program**

June 2016

Publishing Information

'Australian Cross Disability Alliance (ACDA) Submission to the Review of the National Disability Advocacy Program Discussion Paper'

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Contents

1. Australian Cross Disability Alliance (ACDA)	3
2. Introduction.....	4
3. Recommendations.....	4
4. Overarching Comments.....	8
4.1 Human Rights Framework	9
4.2 Role of Disabled People’s Organisations (DPOs)	11
4.3 Investment in the National Disability Advocacy Program	12
5. Responses to Specific Questions	15
5.1 Models of advocacy	15
5.2 Improving access to advocacy supports	16
5.3 Improving the advocacy evidence base and coordination on systemic issues	29
5.4 The interface with the NDIS and addressing conflict of interest.....	30
5.5 Understanding and improving access to justice.....	31

1. Australian Cross Disability Alliance (ACDA)

The Australian Cross Disability Alliance (ACDA) is an alliance of national Disabled People's Organisations (DPOs) in Australia. DPOs are organisations that are led by, and constituted of people with disability.

The key purpose of the ACDA is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes and strategic priorities and opportunities.

The ACDA was founded by, and is made up of four national population specific and cross-disability DPOs that have been funded by the Australian Government to be the recognised coordinating point between Government/s and other stakeholders, for consultation and engagement with people with disability in Australia.

The four ACDA members are:

[Women With Disabilities Australia \(WWDA\)](#) is the national cross-disability DPO for women and girls with all types of disabilities in Australia. It operates as a transnational human rights organisation and is run by women with disabilities, for women with disabilities. WWDA's work is grounded in a human rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights.

[First Peoples Disability Network Australia \(FPDNA\)](#) is the national cross-disability DPO representing Aboriginal and Torres Strait Islander people with disability and their families. FPDNA utilises a range of strategies in its representative role, including through the provision of high-level advice to governments, and educating the government and non-government sectors about how to meet the unmet needs of Aboriginal and Torres Strait Islander people with disability.

[People with Disability Australia \(PWDA\)](#) is the national cross disability rights and advocacy organisation run by and for people with disability. Working within a human rights framework, PWDA represents the interests of people with all kinds of disability. Its primary membership is made up of people with disability and organisations primarily constituted by people with disability. It also has a large associate membership of other individuals and organisations committed to the disability rights movement.

[National Ethnic Disability Alliance \(NEDA\)](#) is the national peak organisation representing the rights and interests of people from Culturally and Linguistically Diverse (CALD/NESB) people with disability, their families and carers throughout Australia. NEDA advocates at the federal level so that CALD/NESB people with disability can participate fully in all aspects of social, economic, political and cultural life.

2. Introduction

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

The ACDA fully supports a strengthened, well resourced and effective program of independent advocacy for people with disability through the National Disability Advocacy Program (NDAP).

This submission responds to the specific questions in the Discussion Paper, but provides some initial overarching comments to frame the views of the ACDA. Some of these comments repeat the views outlined in our submission to the review of the National Disability Advocacy Framework (NDAF).

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

3. Recommendations

The Australian Cross Disability Alliance makes the following recommendations:

- 3.1 that the NDAP review continues ongoing targeted consultation with people with disability, their representative organisations and independent advocacy organisations. This is particularly critical if the NDAP review results in programmatic and funding changes, and decisions regarding tender processes and timeframes.
- 3.2 that DSS conduct regular, ongoing consultation meetings with the ACDA regarding a reformed NDAP, in recognition that the ACDA is the recognised coordinating point for consultation and engagement with people with disability in Australia.
- 3.3 that a vision for a reformed NDAP should focus on:
 - upholding and progressing the human rights of people with disability;
 - being responsive and inclusive of all disability types and geographic locations as well as diverse groups, including Aboriginal and Torres Strait Islander people with disability, women with disability, children and young people with disability, older people with disability, people from Culturally and Linguistically Diverse (CALD) /Non English Speaking Backgrounds (NESB) with disability and people with disability from LGBTIQA communities;
 - interconnections with both the NDIS, the NDS and other national reform agendas;
 - a nationally consistent data collection system that provides the evidence base and benchmarks for progress in achieving human rights as well as emerging human rights issues;
 - a consistent and equitable funding model that recognises and is commensurate with the critical role that independent advocacy performs in advancing the human rights of all people with disability.

- 3.4 Establish and resource a non-government advocacy sector support structure within a DPO, or governed by people with disability, to act as the coordination point for NDAP and a strategic nexus between DPOs and independent advocacy organisations. An advocacy sector support structure must be resourced to enable robust mechanisms and strategies across funding streams and programs to ensure that DPOs and independent advocacy can, at a minimum:
- share information and resources, strategise and collaborate on key human rights issues and outcomes for people with disability, including across Australian jurisdictions, and particularly for systemic and legal advocacy matters;
 - share issues and expertise, develop strategic approaches and provide specific training and support on the provision of independent advocacy support to specific population groups of people with disability, those living in rural, regional and remote areas, and those in socially isolated situations;
 - share and examine the qualitative and quantitative data from NDAP and other program sources to strengthen the human rights evidence base and identify emerging human rights issues;
 - prepare regular report cards for governments and other stakeholders, on the status of human rights for people with disability;
 - establish collaborative working relationships with a wide range of organisations and sectors focused on achieving human rights outcomes.
- 3.5 that a non-government advocacy sector support structure must be genuinely co-designed with DPOs and independent advocacy organisations.
- 3.6 Significantly invest in independent advocacy to:
- match increased advocacy demand in the NDIS environment;
 - progress NDS and broader reform outcomes;
 - address funding shifts to the Commonwealth:
 - at a minimum, levels of funding for NDAP must be equal to the current combined investment from the NDAP and the State or Territory Government, and respond to current levels of unmet need;
 - State and Territory representation and independent advocacy funding provided to the Commonwealth must be retained and allocated for this same purpose within a reformed NDAP;
 - investment, funding and resourcing for representation and independent advocacy must be made available and continue to be the responsibility of Commonwealth and State and Territory Governments;
 - enhance quality and safeguarding.
- 3.7 that a reformed NDAP needs to resource the independent advocacy sector to build expertise and competencies to deliver advocacy support that is individualised and 'fit-for-purpose', that focuses on cross disability advocacy and that fosters collaboration and the sharing of expertise. This should also be built into the NDAP Quality Assurance process.

- 3.8 In line with Australia’s international obligations to advance gender equality and disability rights, all aspects of the NDAP must be gendered. This must include the incorporation of gender perspectives into NDAP goals, structures, priorities, decisions, processes, practices, service agreements, projects, activities, monitoring, and resource allocation, as well as participation at all levels.
- 3.9 Gender statistics, gender disaggregated data and the collection of specific information on the human rights situation of women and girls with disability must be built into all aspects of the NDAP, including monitoring, review and evaluation mechanisms, and should include both quantitative and qualitative approaches and measures.
- 3.10 In keeping with recommendations from the UN treaty monitoring bodies and UN special procedures,¹ the NDAP must include urgent measures to ensure that women with disability are better represented in decision-making and leadership positions, and that structures, mechanisms and initiatives are established within the NDAP at all levels, to enable and foster the effective and meaningful participation of women and girls with disability and their representative organisations.
- 3.11 Service agreements/funding contracts of NDAP agencies must include specific, targeted measures and actions to address the urgent gaps and issues where the NDAP has failed, and continues to fail women and girls with disability. These issues include:
- the right to freedom from violence, abuse, exploitation and neglect;
 - the right to sexual and reproductive freedom, including the right to found and maintain a family;
 - the right to work and to economic security;
 - the right to access to justice, legal capacity and equality before the law
 - the right to decision-making, participation and representation.
- 3.12 Four pillars to enhance access to advocacy for Aboriginal and Torres Strait Islander people with disability:
1. Legal Advocacy
 2. Supported or Individual Advocacy
 3. Systemic Advocacy
 4. Education and Community Development
- 3.13 that a reformed NDAP resource a Legal Advocacy specialisation focused exclusively on the cohort of Aboriginal and Torres Strait Islander people with disability in Australian prisons. At a minimum, this Legal Advocacy specialisation should collocate a legal advocate with 3 Aboriginal Legal Services – Aboriginal Legal Service Western Australia, Aboriginal Legal Service of NSW and Northern Australia Aboriginal Justice Agency in the Northern Territory.
- 3.14 that a reformed NDAP must focus on greater investment on individual advocacy that is Aboriginal owned, managed and operated.

¹ See eg: UN Docs. CEDAW/C/AUL/CO/5; CEDAW/C/AUS/CO/7; CRPD/C/AUS/CO/1; A/67/227; CRPD/C/14/R.1; A/HRC/31/62.

- 3.15 that a reformed NDAP must resource an Aboriginal led systemic advocacy focus, and that this focus should be genuinely co-designed with FPDN.
- 3.16 that a tailored advocacy program that includes community development and a focus on outreach is developed and resource under NDAP. This tailored advocacy program should be should be genuinely co-designed with FPDN.
- 3.17 robust mechanisms need to be in place to ensure the key issues and areas of concern impacting on CALD people with disability are identified, collated and acted upon at both at the state and/or territory and federal systemic advocacy levels.
- 3.18 a reformed NDAP must significantly strengthen funding and resourcing for CALD disability advocacy organisations.
- 3.19 independent advocacy organisations must be appropriately funded to meet the needs of CALD people with disability in their local communities throughout all of Australia. This will allow them to:
- Facilitate and deliver disability advocacy, in all its forms, to CALD communities; a particular emphasis should be placed on self-advocacy, peer-advocacy and community advocacy programming.
 - Engage in relationship building and outreach with CALD communities, creating awareness around the services disability advocacy organisations can provide i.e. to directly target CALD communities in an effort to promote access into disability advocacy services/programs.
 - Ensure that all advocacy services are culturally respectful, inclusive and responsive (e.g. meeting the disability, cultural, religious, language and communication needs of CALD people with disability)
 - Engage in stakeholder networking and relationship building to link with local disability and/or multicultural services and organisations and communities to 1) better support CALD people with disability, and 2) work to remove the barriers CALD people with disability currently face and thus promote social, economic and cultural inclusion of CALD people with disability.
- 3.20 that a reformed NDAP values and resources outreach and engagement and partnership approaches and models to strengthen independent advocacy support to people with disability in rural, regional and remote locations.
- 3.21 that a reformed NDAP values and resources a concerted outreach and engagement approach to independent advocacy for people who are socially isolated.
- 3.22 that DSS consult with independent advocacy to develop mechanisms and processes to address 'refusal of entry' issues for independent advocacy.
- 3.23 that competency in communicating with people with disability, including using supported decision making principles and processes are integral to the delivery of independent advocacy.

- 3.24 A reformed NDAP must as a priority, establish a baseline of human rights based disaggregated data against which future progress towards compliance with the UN treaties (to which Australia is a party) can be measured and monitored.
- 3.25 The advocacy sector support structure coordinate the public availability of NDAP data for the human rights advocacy sector, including the preparation of independent annual report cards on the status of human rights for people with disability.
- 3.26 The advocacy sector support structure collaborate with State and Territory systemic advocacy organisations and coordinating points to strengthen collaborative systemic advocacy priorities and activities across a broad range of government and non-government organisations.
- 3.27 that DSS and the NDIA conduct a targeted forum with DPOs and independent advocacy organisations to examine conflicts of interest and possible mechanisms, policies and funding requirements that can address conflicts that arise at the interface between NDAP funded activities and the NDIS.
- 3.28 The Australian Government act on the recommendations from recent reports and inquiries, including by incorporating recommendations into the National Disability Strategy, to ensure action is taken to address violations of human rights experienced by people with disability in accessing justice.
- 3.29 DSS and the Attorney General’s Department work in partnership with DPOs and independent advocacy organisations to examine good practice models² of specialist legal advocacy, coordinate the delivery of legal advocacy for people with disability across funding streams and service sectors, and facilitate reinvestment in the community legal sector and in legal aid to address the significant access to justice issues facing people with disability.
- 3.30 A reformed NDAP must resource disability specialist legal centres within each State and Territory and at the national level that are able to provide specialist legal assistance to all people with disability.

4. Overarching Comments

Independent advocacy aims to uphold and advance the human rights of people with disability, and should be viewed as a critical, integral component to the disability reform agenda encapsulated by the National Disability Insurance Scheme (NDIS) and the National Disability Strategy (NDS). This reform agenda is underpinned by the international human rights obligations of all Australian governments.

However, the role of independent advocacy has largely been ‘sidelined’ from the disability reform agenda, and often viewed as of lesser importance than the role of services and support systems. While there has been a significant injection in funding and resourcing for disability workforce development and service provider transitioning to the NDIS, there has been little to no change in NDAP funding for independent advocacy for several years. This means that independent advocacy is severely stretched and under increasing pressure to meet demand. This is particularly

² For example, the Criminal Justice Support Network conducted by the Intellectual Disability Rights Service in NSW.

concerning given independent advocacy is largely directed at supporting the human rights of people with disability in the most marginalised and vulnerable situations.

While the ACDA acknowledges that the NDAP review may require “the advocacy sector... to adjust in significant ways”,³ this review must be the opportunity to redress the significant lack of investment and focus on the critical role of independent advocacy for people with disability.

We also note that this review is taking place at the same time as critical interconnecting frameworks and plans are still being finalised. The NDIS Commissioning Framework for Information, Linkages and Capacity Building (ILC) and the NDIS Quality and Safeguarding Framework have not yet been finalised, nor has the second implementation plan for the NDS. The 2015 review of the National Disability Advocacy Framework (NDAF), which guides the NDAP has not as yet resulted in agreement or release of a revised NDAF. The review of NDAP needs to ensure that it is responsive to the final aims, objectives and actions of these frameworks so that NDAP is enhanced in its role as an integral component of the disability reform agenda.

In addition, there are other critical national frameworks and plans that intersect with the disability reform agenda, such as the third action plan under the National Plan to Reduce Violence against Women and their Children 2010-2022, the third action plan under the National Framework for Protecting Australia’s Children 2009-2020, the National Indigenous Reform Agenda ‘Closing the Gap’, Delivering Services To Multicultural Australia 2012 – 2016. A reformed NDAP must ensure coherence with broader national reform agendas.

In this context, the ACDA recommends:

- **that the NDAP review continues ongoing targeted consultation with people with disability, their representative organisations and independent advocacy organisations. This is particularly critical if the NDAP review results in programmatic and funding changes, and decisions regarding tender processes and timeframes.**
- **that DSS conduct regular, ongoing consultation meetings with the ACDA regarding a reformed NDAP, in recognition that the ACDA is the recognised coordinating point for consultation and engagement with people with disability in Australia.**

4.1 Human Rights Framework

The Discussion Paper points out that the NDAP review has largely been prompted by the rollout of the NDIS. It sets out a vision for a reformed NDAP, and then moves to a set of issues and questions that aim to assist in achieving this vision.

However, a reformed NDAP should not only be viewed within an NDIS lens as this limits the vision to how NDAP interacts with “new models of service delivery, market development, and change in opportunities for people with disability...”, and “what elements of advocacy need to be provided within the NDAP, and what will be provided by the NDIS”.⁴

A reformed NDAP should significantly strengthen the NDAP objective of ensuring “people with disability are provided access to effective disability advocacy that promotes, protects and ensures

³ Department of Social Services, ‘Review of the National Disability Advocacy Program Discussion Paper’, April 2016, p.3

⁴ Department of Social Services, ‘Review of the National Disability Advocacy Program Discussion Paper’, April 2016, p.3

their full equal enjoyment of all human rights, enabling full community participation”.⁵ NDAP is a critical component of achieving human rights outcomes for people with disability, not just in relation to the NDIS but also in relation to the NDS and other broader national reform frameworks.

The NDAP review needs to begin with a vision that is underpinned by human rights and that recognises the critical, common link to the human rights principles and objectives outlined in the NDIS and the NDS. The NDS is the strategy agreed by all Australian governments to implement and report to the United Nations (UN) against progress in achieving the Convention on the Rights of Persons with Disabilities (CRPD).⁶ The NDS adopts the principles within the CRPD⁷ and aligns the NDS six policy areas to the CRPD.⁸ 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 core human rights treaties that Australia has ratified. 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.**

While responses to the issues and questions in the Discussion Paper will be important, they will need to be assessed in the context of human rights, rather than just the implications of the rollout of the NDIS and the limited vision for a reformed NDAP that is outlined on page 3 of the Discussion Paper.

With regard to the vision, we specifically note with concern the limiting number of identifying characteristics that pertain to people with disability – “age, disability type, cultural background and place of residence”. If a reformed NDAP is to respond to the individual and systemic issues of all people with disability then it must be responsive and inclusive of all aspects of a person’s identity.

The ACDA recommends that a vision for a reformed NDAP should focus on:

- **upholding and progressing the human rights of people with disability;**
- **being responsive and inclusive of all disability types and geographic locations as well as diverse groups, including Aboriginal and Torres Strait Islander people with disability, women with disability, children and young people with disability, older people with disability, people from Culturally and Linguistically Diverse (CALD) /Non English Speaking Backgrounds (NESB) with disability and people with disability from LGBTIQA communities;**
- **interconnections with both the NDIS, the NDS and other national reform agendas;**
- **a nationally consistent data collection system that provides the evidence base and benchmarks for progress in achieving human rights as well as emerging human rights issues;**
- **a consistent and equitable funding model that recognises and is commensurate with the critical role that independent advocacy performs in advancing the human rights of all people with disability.**

⁵ Ibid. p. 2

⁶ Council of Australian Governments, *National Disability Strategy 2010-2020*, Commonwealth of Australia 2011, pp. 16-17

⁷ Ibid p. 22

⁸ Ibid p. 17

4.2 Role of Disabled People's Organisations (DPOs)

DPOs are governed by, led by and constituted of people with disability, and have significant connections and engagement with their membership and constituents of people with disability.

The ACDA recognises the mutually beneficial advocacy roles played by DPOs and independent advocacy organisations. DPOs and independent advocacy organisations should have the same underpinning human rights objectives. Across Australia, a number of DPOs are funded by the Commonwealth and / or State or Territory Governments as representative organisations of people with disability, some are also NDAP funded, or funded by State or Territory governments to provide advocacy assistance to individuals and groups of people with disability,⁹ and advocacy to effect systemic change (systemic and legal advocacy).¹⁰ DPOs and independent advocacy organisations often collaborate and work in partnership on individual, group and systemic advocacy issues, and this should be enhanced in a reformed NDAP.¹¹

A human rights framed NDAP should recognise the role ascribed to DPOs within the CRPD. The CRPD provides obligations to ensure that people with disability, through our representative organisations are the main participants in CRPD implementation. The UN Special Rapporteur on the Rights of Persons with Disabilities has recently stressed that representative organisations of people with disability, or DPOs, are the focus of CRPD obligations as distinct from organisations *for* people with disability.¹²

DPOs have a direct connection to the issues and concerns of people with disability through their membership and their constituency.¹³ The NDAP is directed at supporting the human rights of people with disability in the most marginalised and vulnerable situations, and the membership and constituency of DPOs is largely made up of the very same people with disability. For example, the membership of the ACDA member organisations includes people with disability who have experienced or continue to experience significant human rights violations and hardships, including contact with the criminal justice system, living in institutions, experiencing domestic violence, being forcibly sterilised, having their children taken from them, being forced to live in segregated and congregate environments, being homeless, being denied a visa or residency on the basis of disability, living in poverty.

Independently and collectively, the ACDA has advocated on these significant human rights issues for people with disability at the State, national and international levels. Sometimes we have worked in partnership with other independent advocacy organisations, but in many instances it

⁹ This includes individual, group, citizen, legal and self-advocacy support.

¹⁰ For example, PWDA is funded by the Commonwealth as a national peak organisation of people with disability, funded by the NSW Government as a NSW peak organisation of people with disability (representation, systemic and legal advocacy) and an individual advocacy provider for a Boarding House individual and group advocacy project, and is also an NDAP funded organisation for the provision of systemic and individual advocacy in NSW and five locations in QLD.

¹¹ For example, the NSW Disability Advocacy Network (NDAN) brings together independent advocacy organisations in NSW, including DPOs providing advocacy to discuss and progress common issues.

¹² For more detail on the key role of DPOs, see UN Special Rapporteur on the Rights of Persons with Disabilities, 'Report of the Special Rapporteur on the rights of persons with disabilities', UN Doc A/HRC/31/62, Agenda item 3.

¹³ Many people with disability do not join organisations because they are living in very marginalised and isolated situations and membership of DPOs is irrelevant to their daily lives. Nevertheless, DPOs work to represent human rights issues and concerns for all people with disability, both our members and the broader constituency of people with disability.

has only been the ACDA that has put critical human rights issues onto the disability and mainstream human rights agenda.

Regardless of advocacy role and funding source, DPOs have a critical role in a reformed NDAP given the focus of NDAP is on promoting and protecting our human rights, and the obligation within CRPD to ensure that people with disability through representative organisations of people with disability are involved in policy development and decision-making processes affecting our lives.

In response to this CRPD obligation and to the specific questions raised in the Discussion Paper, the ACDA proposes the following overarching recommendation:

Establish and resource a non-government advocacy sector support structure within a DPO, or governed by people with disability, to act as the coordination point for NDAP and a strategic nexus between DPOs and independent advocacy organisations. An advocacy sector support structure must be resourced to enable robust mechanisms and strategies across funding streams and programs to ensure that DPOs and independent advocacy can, at a minimum:

- **share information and resources, strategise and collaborate on key human rights issues and outcomes for people with disability, including across Australian jurisdictions, and particularly for systemic and legal advocacy matters;**
- **share issues and expertise, develop strategic approaches and provide specific training and support on the provision of independent advocacy support to specific population groups of people with disability, those living in rural, regional and remote areas, and those in socially isolated situations;**
- **share and examine the qualitative and quantitative data from NDAP and other program sources to strengthen the human rights evidence base and identify emerging human rights issues;**
- **prepare regular report cards for governments and other stakeholders, on the status of human rights for people with disability;**
- **establish collaborative working relationships with a wide range of organisations and sectors focused on achieving human rights outcomes.**

The ACDA further recommends that a non-government advocacy sector support structure must be genuinely co-designed with DPOs and independent advocacy organisations.

4.3 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 recommendations:

4.3.1 Significantly invest in independent advocacy to match increased advocacy demand in the NDIS environment.

There has been significant investment in service provider sector development, but little to none in the disability advocacy sector in the context of the NDIS. Yet the NDIS is a major reform that has brought significant change to the lives of people with disability, increased demand for all forms of advocacy, and increased need for disability advocates to quickly acquire new knowledge and expertise.

For example:

- NDIS participants are seeking 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 advocacy plays a key role in assisting with these issues at both the individual and systemic levels. This 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.
- The transition to the NDIS is rapidly changing the structure of disability service provision and this places increased pressure on independent advocacy to participate on advisory groups, to provide input into service design and delivery and to provide expert, practical advice to a broad range of service systems, such as health, housing, education, and the justice system.
- In the changing disability service landscape, disability advocacy is often the only constant independent support for people with disability. Independent advocacy is increasingly being called upon by people with disability, families, government and service providers to assist with individual service issues and systemic advice in relation to policy and legislative frameworks. The impact and value of this role is largely not understood, unrecognised and underestimated.

4.3.2 Significantly invest in independent advocacy to progress NDS and broader reform outcomes.

For the NDIS to be successful, there must be parallel progress in achieving the outcomes in the six policy areas under the NDS – inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; health and wellbeing.

This requires investment in enhancing the capacity of independent advocacy to address individual and systemic issues arising in a wide range of service systems, policy development areas and legislative frameworks and across Commonwealth, State and Territory jurisdictions, such as ensuring equity of support in the aged care system, accessing inclusive education, accessing consumer complaint bodies, ensuring appropriate, accessible housing, preventing and responding to violence and abuse, addressing employment discrimination and accessing the justice system.

4.3.3 Significantly invest in independent advocacy to address funding shifts to the Commonwealth.

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

The NDAP must be able to respond to this situation to ensure equity of advocacy support for people with disability between States and Territories and to retain systemic expertise in policy and legislative arrangements within jurisdictions and local level advocacy for individuals.

In relation to this issue, the ACDA specifically recommends that:

- **at a minimum, levels of funding for NDAP must be equal to the current combined investment from the NDAP and the State or Territory Government, and respond to current levels of unmet need.**
- **State and Territory representation and independent advocacy funding provided to the Commonwealth must be retained and allocated for this same purpose within a reformed NDAP.**
- **investment, funding and resourcing for representation and independent advocacy must be made available and continue to be the responsibility of Commonwealth and State and Territory Governments.**

4.3.4 Significantly invest in independent advocacy to enhance quality and safeguarding.

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 people with disability who are not NDIS eligible will need increasing support to navigate and adapt to the new market based disability support and mainstream service environment; governments will still need consultation mechanisms to develop and implement effective laws and policy; and independent advocacy will be needed to ensure that the market for disability supports grows and responds in a way which promotes and upholds human rights.

People with disability will also seek independent advocacy support to navigate disability and mainstream complaints handling and safeguarding systems, these systems will require advice and expertise in relation to disability inclusion and accessible response strategies, and there will need to be mechanisms to strongly interlink these systems with independent advocacy support. This is particularly critical if complaints handling and safeguarding systems are moved to the private sector, such as the recently announced changes to 1800 Respect counseling services, which will now have a triage function conducted by Medibank Health Solutions.

The critical role of independent advocacy in quality and safeguarding, particularly in relation to prevention and response to the significantly high incidence of violence, abuse and neglect experienced by people with disability has been emphasised in a number of recent Commonwealth and State inquiries and investigations, including:

- Senate Standing Committee on Community Affairs Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability;¹⁴

¹⁴ Available at:

<http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report>

- Senate Standing Committee on Community Affairs Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia;¹⁵
- Parliament of Victoria, Joint Investigatory Committee, Family and Community Development Inquiry into Abuse in Disability Services;¹⁶
- Victorian Ombudsman Investigation into disability abuse reporting.¹⁷

No support, complaints or safeguarding 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 quality and safeguarding in both the NDIS and mainstream systems must be recognised, enhanced and resourced.

5. Responses to Specific Questions

5.1 Models of advocacy

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

What are the drawbacks?

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

The ACDA agrees with the statements in the Discussion Paper that “[a] better situation would be that advocacy support is available in all locations to assist individuals with disability address their specific issues and needs”; “[t]he exact manner in which that advocacy is provided will depend on each person’s situation”; “the focus should be on the human rights of the person with disability and their individual needs and not on what model of advocacy is available in their local area”.¹⁸ In order to achieve this, there will need to be significant investment in NDAP, as well as a focus on cross disability independent advocacy that has the expertise to respond and tailor advocacy support to meet individual needs and respond to systemic issues, including those relevant to particular population groups, such as women, children, Aboriginal and Torres Strait Islander people, people from CALD / NESB and people with disability from LGBTIQ communities.

Cross disability advocacy already exists that provides a range of advocacy support depending on the person and the situation, such as self-advocacy support, individual and group advocacy, legal advocacy and systemic advocacy,¹⁹ but this will need to be strengthened. This is particularly

¹⁵ Available at:

<http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Report>

¹⁶ Available at: <<http://www.parliament.vic.gov.au/fcdc/inquiry/397>>

¹⁷ Available at: <<https://www.ombudsman.vic.gov.au/Investigations/Investigation-into-disability-abuse-reporting>>

¹⁸ Department of Social Services, ‘Review of the National Disability Advocacy Program Discussion Paper’, April 2016, p.4

¹⁹ For example, PWDA provides cross-disability advocacy that assists people to self-advocate, supports people through individual advocacy, conducts group advocacy, provides legal advocacy and systemic advocacy based on individual issues.

critical in locations where there is no other disability advocacy support, or where the only independent advocacy available focuses on a specific type of advocacy that is not suitable for the person and / or that only works with people with specific types of disability.

Where DPOs and independent advocacy are more readily available, including independent advocacy that is directed at a specific model of advocacy or is directed at people with specific types of disability, then there also needs to be a focus on building stronger linkages and referral pathways and working collaboratively to share expertise and respond to individual needs and systemic issues. Many independent advocacy organisations and DPOs already work closely together in this way, as well as participate in state-wide formal meetings of independent advocacy organisations.²⁰ This could be strengthened.

The ACDA recommends that a reformed NDAP needs to resource the independent advocacy sector to build expertise and competencies to deliver advocacy support that is individualised and ‘fit-for-purpose’, that focuses on cross disability advocacy and that fosters collaboration and the sharing of expertise. This should also be built into the NDAP Quality Assurance process.

5.2 Improving access to advocacy supports

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?*

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

The ACDA is extremely concerned about the significant gaps in the availability of independent advocacy and gaps in the expertise of providing independent advocacy for particular groups of people with disability.

While PWDA is the only ACDA member organisation providing independent advocacy funded under NDAP, WWDA, FPDN and NEDA report that they spend considerable unfunded time in providing individual advocacy support to people with disability who have not been able to obtain advocacy or appropriate advocacy for their specific circumstances. In many situations, these individuals have been on a lengthy ‘referral roundabout’ that can involve disability advocacy and support systems, women’s services, multicultural agencies, Aboriginal and Torres Strait Islander support agencies and mainstream support organisations. The common factor is the lack of expertise and focused support that addresses the intersections of gender and disability, cultural and linguistic diversity and disability, and Aboriginal and Torres Strait Islander identity and disability. The ACDA highlights the following in this respect:

²⁰ For example, independent advocacy organisations in NSW formed the NSW Disability Advocacy Network (NDAN) and in QLD, the Combined Advocacy Group QLD (CAGQ) to share information and work together on matters of mutual importance.

5.2.1 Women and girls with disability

In Australia today there are well over 2 million women and girls with disability, making up nearly 20% of all women and girls in Australia.²¹ Women and girls with disability represent one of the most marginalised and excluded groups in Australia. They continue to experience widespread discrimination and violations of their rights and freedoms in all areas, yet are denied opportunities to participate in, and remain largely excluded from, all advocacy and decision-making processes, at both individual and systemic levels.²²

Women and girls with disability have consistently been identified by successive Australian Governments, civil society, and the United Nations as a group requiring **specific, targeted and extra measures** to promote their rights and freedoms, particularly in the areas of violence prevention, economic empowerment, sexual and reproductive rights; decision-making, leadership, representation and participation; access to justice, legal capacity and equality before the law.²³ The CRPD is clear on gender equality. It recognises gender as one of the most important categories of social organisation and prioritises women and girls with disability as a group warranting specific attention, obliging Governments to take positive actions and measures to ensure that women and girls with disability enjoy all human rights and fundamental freedoms.²⁴

Obligations under CRPD Article 6 [Women with disabilities] are of *immediate* nature.²⁵ As such, the rights provided for in Article 6 apply at the moment of ratification and are subject to immediate realisation. This means, that upon ratification, State Parties must immediately begin to take steps towards the realisation of the rights in Article 6. The legal nature of Article 6 is *cross-cutting* in the sense that it accompanies all human rights enshrined in the Convention. All rights must be interpreted in light of Article 6, which means that in relation to women and girls with disability – all rights in the CRPD are subject to immediate realisation. State Parties are under a comprehensive obligation to implement the Convention in consultation with, and involving, “*real, effective and meaningful participation of women and girls with disability and their representative organisations.*”²⁶

Yet despite the CRPD entering into force in Australia in 2008, domestic disability policy, programs and services – including the NDAP – remain un-gendered, and the intersection of gender and disability, along with other elements of intersectionality, continue to be largely ignored. Women and girls with disability in Australia have failed to benefit from provisions in international human

²¹ Australian Bureau of Statistics (2011) Disability, Australia, 2009, Cat. No. 4446.0. Accessed online July 2014 at: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4446.0>

²² Frohmader, C. (2014) ‘Gender Blind, Gender Neutral’: *The effectiveness of the National Disability Strategy in improving the lives of women and girls with disabilities.* Prepared for Women With Disabilities Australia (WWDA), Hobart, Tasmania. ISBN: 978-0-9585268- 2-1. Available online at: http://wwda.org.au/wp-content/uploads/2013/12/WWDA_Sub_NDS_Review2014.pdf

²³ See for eg: Committee on the Rights of Persons with Disabilities (2013) Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013); UN Doc. CRPD/C/AUS/CO/1. See also: Committee on the Elimination of Discrimination against Women, Concluding comments of the Committee on the Elimination of Discrimination against Women: Australia, 3 February 2006, CEDAW/C/AUL/CO/5; See also: Committee on the Elimination of Discrimination against Women (2010) UN Doc. CEDAW/C/AUS/CO/7.

²⁴ See Preamble [q] of UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106.

²⁵ The progressive realisation clause does not apply to non-discrimination duties.

²⁶ Committee on the Rights of Persons with Disabilities (22 May 2015) *General comment on Article 6: Women with disabilities: Draft prepared by the Committee*; Fourteenth session of the Committee on the Rights of Persons with Disabilities, 17 August– 4 September 2015, Item 8 of the provisional agenda. UN. Doc. No: CRPD/C/14/R.1.

rights law that give rise to Australia's obligations in relation to gender equality and to disability rights.

Mapping undertaken by WWDA demonstrates that on average more than 20 hours per week is devoted to individual advocacy for women with disability. Advocacy requests for women with disability come from women themselves, families, support workers, and disability and mainstream service systems. In many situations, people contacting WWDA have been referred by other services or individuals and directly told to contact WWDA. Referrals also come from "crisis services and other services which are specifically funded to undertake individual advocacy."²⁷ In many cases, women with disability are referred from agency to agency without receiving any support or appropriate response to their issues, despite the fact that their issues are often urgent and require immediate response.²⁸

The most common issues that women with disability seek individual advocacy assistance from WWDA include:

- violence, abuse and exploitation, including domestic violence;
- violations of sexual and reproductive rights;
- removal of babies and children from mothers with disability;
- lack of services and support programs;
- legal issues, including discrimination in the Family Court system;
- lack of coordination of care;
- discrimination in employment;
- discrimination in education;
- lack of friendships and supported recreational opportunities;
- confusion and lack of information about the NDIS.²⁹

WWDA also stresses that over the past twenty years, data in relation to the uptake of disability services continues to demonstrate that more men with disability (about 60%) are supported than women with disability (about 40%). This is being replicated in the NDIS trial sites where men and boys are assisted more than women and girls.

The ACDA is extremely concerned that the Discussion Paper completely omits discussion on the specific issues related to the intersection of gender and disability. If a reformed NDAP is genuinely underpinned by human rights, and consistent with the immediate nature of CRPD Article 6, then it has an *obligation* to not only be gendered, but embed, address and resource the specific advocacy expertise and supports required by women and girls with disability.³⁰

The ACDA makes the following recommendations:

- **In line with Australia's international obligations to advance gender equality and disability rights, all aspects of the NDAP must be gendered. This must include the incorporation of gender perspectives into NDAP goals, structures, priorities, decisions, processes, practices,**

²⁷ Women with Disability Australia, *Annual Report: Key International and National Projects, Activities and Achievements, 1 July 2014 – 30 June 2015*, WWDA p.11.

²⁸ Ibid.

²⁹ Ibid p. 11-12.

³⁰ The rights of women are articulated in the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and these rights are elaborated for women and girls with disability specifically in article 6 of the CRPD as well as generally throughout the other articles of the CRPD.

service agreements, projects, activities, monitoring, and resource allocation, as well as participation at all levels.

- **Gender statistics, gender disaggregated data and the collection of specific information on the human rights situation of women and girls with disability must be built into all aspects of the NDAP, including monitoring, review and evaluation mechanisms, and should include both quantitative and qualitative approaches and measures.**
- **In keeping with recommendations from the UN treaty monitoring bodies and UN special procedures,³¹ the NDAP must include urgent measures to ensure that women with disability are better represented in decision-making and leadership positions, and that structures, mechanisms and initiatives are established within the NDAP at all levels, to enable and foster the effective and meaningful participation of women and girls with disability and their representative organisations.**
- **Service agreements/funding contracts of NDAP agencies must include specific, targeted measures and actions to address the urgent gaps and issues where the NDAP has failed, and continues to fail women and girls with disability. These issues include:**
 - **the right to freedom from violence, abuse, exploitation and neglect;**
 - **the right to sexual and reproductive freedom, including the right to found and maintain a family;**
 - **the right to work and to economic security;**
 - **the right to access to justice, legal capacity and equality before the law**
 - **the right to decision-making, participation and representation.**

5.2.2 Aboriginal and Torres Strait Islander communities and their families

By any measure Aboriginal and Torres Strait Islander people with disability are amongst the most disadvantaged Australians. They often face multiple barriers to their meaningful participation within their own communities and the wider community. The vast majority of Aboriginal and Torres Strait Islander people with disability are at the periphery of all aspects of the disability services sector. In accessing individual advocacy services this is particularly acute, despite the fact that in many ways Aboriginal and Torres Strait Islander people with disability are the group within the Australian community who are most in need of individual advocacy support. FPDN states that meeting the needs of Aboriginal and Torres Strait Islander people with disability is one of the most critical social justice issues in Australia today.

The prevalence of disability amongst Aboriginal and Torres Islanders is significantly higher than of the general population. Until recently the prevalence of disability in Aboriginal and Torres Strait Islander communities has been only anecdotally reported. However the 2011 Census concluded that at least 50% of all Aboriginal and Torres Strait Islander people have some form of disability or long-term health condition. This equates to approximately 350,000 Aboriginal and/or Torres Strait Islander people with disability in Australia today. Regrettably the fact remains that governments have been slow to realise the high prevalence of disability in Aboriginal and Torres Strait Islander communities and still today this prevalence data is not widely known. Indeed at the time when the National Disability Advocacy Program was first developed in the 1980's it would appear that Aboriginal and Torres Strait Islander people with disability were not mentioned.

³¹ See eg: UN Docs. CEDAW/C/AUL/CO/5; CEDAW/C/AUS/CO/7; CRPD/C/AUS/CO/1; A/67/227; CRPD/C/14/R.1; A/HRC/31/62.

The high prevalence of disability, approximately twice that of the non-indigenous population, occurs in Aboriginal and Torres Strait Islander communities for a range of social reasons, including poor health care, poor nutrition, exposure to violence and psychological trauma (e.g. arising from removal from family and community) and substance abuse, as well as the breakdown of traditional community structures in some areas. Aboriginal people with disability are significantly over-represented on a population group basis among homeless people, in the criminal and juvenile justice systems,³² and in the care and protection system (both as parents and children).³³

Historically much of the focus on Aboriginal people with disability has been from a health perspective. Whilst this is essential, particularly regarding primary health interventions, it has come at the cost of failing to recognise the social aspects of Aboriginal disability. This has meant that the barriers that produce discrimination against Aboriginal people with disability remain firmly entrenched and the general well being of Aboriginal people with disability has not improved in any meaningful way.

Furthermore the impact of colonisation and the resultant dispossession of land and displacement from places of cultural significance have had an impact on the lives of many Aboriginal people with disability which is difficult to measure.

All of these factors contribute to the fact that disability rights from an Aboriginal and Torres Strait Islander perspective is an emerging social movement. In many ways this social movement is starting from a baseline position.

Many Aboriginal and Torres Strait Islander people with disability are in urgent need of advocacy support. Currently the number of Aboriginal and Torres Strait Islander people with disability accessing independent advocacy services is very small. One of the most basic reasons why this continues to occur is that many Aboriginal and Torres Strait Islander people with disability do not in fact identify as people with disability. This occurs for a range of reasons including:

- Why would you identify as a person with disability when you already experience discrimination based on your Aboriginality; i.e. why take on another perceived negative label.
- In traditional language there was no comparable word to disability, which suggests that disability may have been accepted as part of the human experience.
- Or in some communities particularly communities that continue to practice a more traditional lifestyle disability may be viewed as a consequence of 'married wrong way.' That is many Aboriginal people with disability and their parents and family members experience stigma related to a kind of 'bad karma' type view of disability.
- A predominance of the medical model of disability has had a profoundly negative impact on the lives of many Aboriginal and Torres Strait Islander people with disability. Much of the

³² Aboriginal people are 11 times more likely to be imprisoned than other Australians. Source: *Overcoming Indigenous Disadvantage Key Indicators 2005; Steering Committee for the Review of Government Service Provision*. There is no empirical evidence to quantify the number of Aboriginal people with disability in particular with intellectual disability and mental illness in the criminal justice system. The prevalence of intellectual disability for instance in the prison population is often contested with wide variation in percentages. However a report by the Law Reform Commission published in 1996 entitled *People with an Intellectual Disability and the Criminal Justice System* noted that 12-13% of the prison population were people with an intellectual disability.

³³ *Overcoming Indigenous Disadvantage Key Indicators 2005; Steering Committee for the Review of Government Service Provision* states 'The rate of children on care and protection orders (for a combination of all states and territories except NSW) was five times higher for indigenous children (20 per 1000 children in the population aged 0 – 17 years) than for non-indigenous children (4 per 1000 children). Pg 9.5

focus on contemporary Indigenous Australia relates to the *Closing the Gap* campaign. This campaign whilst essential often focuses heavily on primary health interventions. This does not address the whole of life needs of Aboriginal and Torres Strait Islander people with disability. An example of this includes recognition, rightfully of the high prevalence of hearing impairment amongst young Aboriginal children and a concerted campaign to address this. What tends to happen however is that many Aboriginal children are getting their hearing impairment treated however their accompanying learning disability which has occurred because of extended periods without proper hearing does not get addressed. This results in only part of the job being done, that is a medical intervention has taken place but a 'social model of disability' intervention around the more long term related impairment has not.

In many ways 'disability' is a new conversation in Aboriginal and Torres Strait Islander communities. Put simply, in some ways the movement supporting Aboriginal and Torres Strait Islander people with disability is not unlike the way disability was viewed in the rest of Australian society some fifty to hundred years ago.

A model of advocacy

It must be noted that FPDN has never been funded under NDAP, yet provides significant individual advocacy support. However, the approach that FPDN takes to advocacy differs in many ways to that undertaken by mainstream providers. This is because of the reasons outlined earlier, including that in many ways 'disability' is a new conversation in many Aboriginal and Torres Strait Islander communities. Therefore it is critical that communities across the country be given the opportunity to discuss 'disability'.

Furthermore the type of advocacy required includes engagement not only with the individual but the wider family and the community. Advocacy for Aboriginal and Torres Strait Islander people with disability is invariably complex in nature, and very rarely issue based. Once a relationship is established with an advocate, then that advocate will likely be required to provide support in a range of additional ways that are not easily defined as traditional advocacy support. FPDN regularly undertakes work that is outside the work that it is funded to do.

For example, in regional and remote Australia, it is commonplace for FPDN staff to be required to drive community members between communities as the staff member may be the only person with a car in the community at the time they are visiting. It is FPDN policy that before visiting communities, we purchase groceries for the communities. Before visiting regional and remote communities FPDN staff take clothes and other supplies to communities. This is because in many of the communities in which FPDN works, Aboriginal people including Aboriginal people with disability are living in abject poverty. Such responsibilities or measures are not well understood when it comes to recognition of the diverse nature of advocacy that is necessary for Aboriginal and Torres Strait Islander people with disability.

A standard process that the FPDN uses for individual advocacy is to call a community gathering of all interested people to discuss 'disability'. At the end of the community forum private interviews are held with individuals, which act as formal intakes for individual advocacy matters. The reason why this approach is done, and why it continues to prove so successful is firstly, by holding a community gathering people can learn their rights and entitlements as carers or as people with disability in a safe environment. It also has the potential to influence the wider community because a broad cross section of people from that community is likely to attend.

The FPDN argues strongly that there needs to be equal investment paid to community development in addition to individual advocacy.³⁴ This is the only practical way in which change will begin to occur. Getting outcomes for individuals whilst critical will not change whole community perception necessarily. It is also inconsistent with a more Indigenous approach to life in general of one of solidarity and whole of community well-being.

The ACDA recommends four pillars to enhance access to advocacy for Aboriginal and Torres Strait Islander people with disability:

- 5. Legal Advocacy**
- 6. Supported or Individual Advocacy**
- 7. Systemic Advocacy**
- 8. Education and Community Development**

Legal Advocacy

Based upon more than a decade of community engagement with Aboriginal and Torres Strait Islander people with disability, FPDN has regularly encountered stories of discriminatory interactions with the criminal justice system. It is a well-established fact that people with disability often experience discrimination in their interactions with the justice system, this includes interactions with police, the courts and judicial system more generally, and this is particularly acute for Aboriginal and Torres Strait Islander people with disability.

It is also unclear how many Aboriginal people with disability are actually in the Australian prison system. A recent report by the University of NSW, *A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system* has estimated that there are at least 676 Aboriginal people with cognitive or psychosocial disability in the prison population in NSW and that with appropriate advocacy support before their interactions with police, a significant number of these Aboriginal people with disability could have avoided prison altogether. It is not known how many Aboriginal and/or Torres Strait Islander people with disability are in prisons around Australia in other jurisdictions.

The following example starkly illustrates the need for legal advocacy. FPDN recently met with staff from the Youth Koori Court in Western Sydney. Staff, including the magistrate advised that they currently have 50 young Aboriginal people appearing before the Youth Koori Court, and that at least 20 of the 50 young Aboriginal people have significant disability. None of these 20 young people are currently receiving any meaningful support for their disability. Furthermore, as the NSW government has delegated its responsibilities for disability support to the NDIS, all of these young people are at a very great risk of falling through service system gaps completely, especially for those young people who are not considered to be severely or profoundly disabled.

The ACDA recommends that a reformed NDAP resource a Legal Advocacy specialisation focused exclusively on the cohort of Aboriginal and Torres Strait Islander people with disability in Australian prisons. At a minimum, this Legal Advocacy specialisation should collocate a legal advocate with 3 Aboriginal Legal Services – Aboriginal Legal Service Western Australia, Aboriginal Legal Service of NSW and Northern Australia Aboriginal Justice Agency in the Northern Territory.

³⁴ This is also the experience of PWDA individual advocates working in remote Aboriginal communities in QLD. For example, to address an advocacy matter for an individual may involve working with the community to maintain consistent and regular water supply into the community.

While it is highly likely that these 3 legal advocates will quickly be overwhelmed in terms of caseload, this at least will begin to address this urgent often overlooked area of need.

Supported or Individual Advocacy

Historically access to individual advocacy for Aboriginal and Torres Strait Islander people with disability has been very poor. Indeed, when the NDAP was first established it would appear that Aboriginal and Torres Strait Islander people with disability were not referred to.

FPDN and its newly merged partner organisation, the Aboriginal Disability Network NSW (ADN NSW) have undertaken individual advocacy for Aboriginal and Torres Strait Islander people with disability for more than a decade, but in an entirely unfunded capacity. This has meant that the disadvantage experienced by Aboriginal and Torres Strait Islander people with disability has become only further entrenched. Those Aboriginal and Torres Strait Islander people with disability who have accessed individual advocacy services under the NDAP have done so largely due to referral from either the ADN NSW or FPDN.

It is well-established that Aboriginal people with disability and their families want to engage directly with Aboriginal advocates. This is for a range of reasons including the fact that Aboriginal people feel culturally safe talking with other Aboriginal people. The often sensitive nature of the conversation and the perceived or actual risks for some families of drawing unwanted attention of government authorities, means that the most effective and meaningful way to provide advocacy to Aboriginal people with disability and their families is by Aboriginal people and organisations.

The ACDA recommends that a reformed NDAP must focus on greater investment on individual advocacy that is Aboriginal owned, managed and operated.

Systemic Advocacy

Systemic Advocacy is fundamental to creating meaningful change for all people with disability; however it is particularly acute for Aboriginal and Torres Strait Islander people with disability. The fact remains that there is still very little data, research and reference material on disability in Aboriginal Australia to provide an evidence base and as a consequence very little policy development has occurred to date. It is only very recently that there have been moves towards establishing a *National Action Plan for Indigenous People with Disabilities* for instance.

There has never been any meaningful targeted systemic advocacy funding under NDAP for Aboriginal and Torres Strait Islander people with disability. While FPDN and the ACDA play a critical systemic advocacy role and an obvious focal point for future resourcing of systemic advocacy, it is critical that there is an Aboriginal led systemic advocacy focus within NDAP.

The ACDA recommends that a reformed NDAP must resource an Aboriginal led systemic advocacy focus, and that this focus should be genuinely co-designed with FPDN.

Education and Community Development

One of the major barriers for the realisation of the human rights of Aboriginal people with disability is an individual acting of their own volition. Much of Aboriginal Australia, particularly in regional and remote Australia is so seriously disenfranchised that the ability and willingness to speak up for oneself is now very seriously diminished. In some communities, Aboriginal people have become highly skilled at saying what they believe people from outside, particularly government wants to hear. In addition, many communities have for too long heard too many

empty promises all of which culminates in a deep mistrust of government authority and any outsiders who do not demonstrate a meaningful long-term commitment to community.

To address this distrust it is critical that meaningful relationships be established between Aboriginal and Torres Strait Islander people with disability and advocates, particularly Aboriginal advocates.

The FPDN argues that the outputs to date under NDAP have failed Aboriginal and Torres Strait Islander people with disability miserably. There currently does not exist any substantive Indigenous owned or operated disability advocacy organisation funded under NDAP except for a small organisation located in Western Sydney. Furthermore FPDN research shows that in NSW and Queensland, as much as 75% of the Aboriginal population is not being adequately serviced. There are mainstream organisations that are funded to provide state wide advocacy, or to cover several regions but this is not making any meaningful difference. This is often because of a lack of shopfront presence. Western NSW, the Cape York and Torres Strait Island communities as well as virtually the whole of the Northern Territory is predominantly Aboriginal and/or Torres Strait Islander. For example, in the Orana region of NSW (from Dubbo, west to Broken Hill, south to Condobolin to Bathurst and Orange) there are large Aboriginal populations. The mainstream advocacy provider, if in fact one is funded for some of these regions, would only have resources to visit some of these towns and communities once a year. Such a piecemeal approach will not enable community development nor enable any kind of rapport to be built with the Aboriginal communities in these areas. The FPDN argues that this will result in continuing low numbers of Indigenous people accessing advocacy. The prevalence of disability in Indigenous communities is such that whilst the total population may not be high the proportion of Indigenous people that have disability is high and this therefore justifies a stand-alone advocacy program.

Furthermore a tailored advocacy program as it relates to Aboriginal and Torres Strait Islander people with disability would recognise and value the importance of community development as a key function, and it would resource appropriately a concerted outreach approach that would have much of the advocacy work being undertaken in a 'field work' capacity. A phone based or occasional visit to community approach will simply not work because many Aboriginal and Torres Strait Islander people with disability don't own telephones or they are distrustful of 'fly in fly out' type service delivery. In addition the current approach tends to imply that Aboriginal and Torres Strait Islander people with disability have to come to services as opposed to the service going out to people. If this approach continues then the FPDN argues strongly that the NDAP will continue to see low numbers of Aboriginal and Torres Strait Islander people with disability accessing the NDAP.

The ACDA recommends that a tailored advocacy program that includes community development and a focus on outreach is developed and resource under NDAP. This tailored advocacy program should be should be genuinely co-designed with FPDN.

5.2.3 People from CALD and/or NESB with disability

People from CALD and/or NESB with disability comprise nearly 25% of the national disability population, meaning that nearly one million Australians with disability are from CALD

backgrounds.³⁵ However, people from CALD or NESB with disability are considerably underrepresented within the disability service system.³⁶

For example, when compared to people with disability born in English speaking countries, people with disability born in a non-English speaking countries 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.³⁷

CALD people with disability 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 background.³⁸ They also need significant advocacy support to obtain access and equity in mainstream service systems, such as health, education, employment, housing, justice, where CALD people with disability experience disproportional low access and utilisation rates.

In addition to disability support needs, CALD people with disability (and their families and carers) also require tailored advocacy support to resolve issues arising from the intersection of disability, language and culture. This includes

- *Cultural related factors*: such as, cultural conceptualisations and differences around disability, caring, social & gender roles; including possible perceived stigma/shame associated with 'disability' or accessing formalised support.
- *Language related factors*: such as, lack of awareness that services or supports are available, including how to access them, how to utilise them, how to voice and resolve concerns and/or complaints; and the inappropriate and/or under-utilisation of accredited interpreters.
- *Migration or Settlement related factors*: such as, people may be newly arrived to Australia and thus navigating the complexities of settlement; have a lived experience of torture and/or trauma; fearful and distrusting of government or services/programs not regularly accessed by members of their community; limited social support and networks resulting in social isolation and lack of informal supports.

The ACDA is concerned that much more work needs to occur to ensure the advocacy needs of CALD people with disability are met. There is only a handful of independent advocacy organisations around Australia that provide tailored and specialised advocacy support to CALD people with disability, their families and communities. Some of these organisations receive resources through the NDAP, however, typically these organisations rely on various funding income streams to deliver advocacy services to CALD people with disability, such as NDAP, State and Territory government funding and sometimes one- off project and/or program funding.

Independent advocacy organisations need to have expertise to work with CALD people with disability, CALD communities, mainstream service systems, non-for-profit organisations and

³⁵ National Ethnic Disability Alliance (NEDA), 2010 'What does the data say?', Available at: <http://neda.org.au/index.php/reports/item/what-does-the-data-say>

³⁶ 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).

³⁷ Ibid.

³⁸ National Disability Insurance Agency, 'NDIA Quarterly Report to COAG Disability Reform Council', 31 December 2014. At: <http://www.ndis.gov.au/document/754>

Government departments to ensure CALD people with disability are heard, and most importantly, supported to self-determine. The ACDA is of the opinion that the advocacy needs of CALD people with disability are best met by accessing:

- 1) Specialised CALD Disability Advocacy organisations;
- 2) Disability advocacy organisations that have demonstrated their expertise, competency, capacity and ability to meet the advocacy needs of CALD people with disability;
- 3) Multicultural advocacy organisations that have demonstrated their expertise, competency, capacity and ability to meet the advocacy needs of CALD people with disability.

However, currently, CALD disability advocacy organisations do not have the funds to expand the effective and vital work that they do; disability advocacy organisations typically do not have the skills, resources and/or capacity to meet the multicultural needs of CALD people with disability; and, multicultural advocacy organisations are often unaware of the disability related issues affecting CALD people with disability.

The gap in advocacy support leaves CALD people with disability with unaddressed disability advocacy needs which reinforces their invisibility within service systems and the policy landscape, and silences their voice at a systemic level. CALD disability advocacy organisations are not only best placed to appropriately and effectively respond to diverse advocacy needs of CALD people with disability, they are also the most equipped to engage in systemic advocacy as expert 'practitioners' within the field - they are comprised of CALD people with disability and/or have built strong relationships with CALD people with disability and their communities, and have a solid understanding of the key issues impacting on CALD people with disability.

While all independent advocacy organisations need to develop their capacity, understanding and ability to respond to the various needs of CALD people with disability, the ACDA is deeply concerned that the voice of CALD people with disability may be diluted or silenced if systemic advocacy and representation is expected to occur organically or proportionally within more mainstream advocacy organisations. Unfortunately, this will be the case if CALD disability advocacy organisations are not funded into the future, or if the gaps in CALD disability advocacy provision remain.

The ACDA recommends that:

- **robust mechanisms need to be in place to ensure the key issues and areas of concern impacting on CALD people with disability are identified, collated and acted upon at both at the state and/or territory and federal systemic advocacy levels.**
- **a reformed NDAP must significantly strengthen funding and resourcing for CALD disability advocacy organisations.**
- **independent advocacy organisations must be appropriately funded to meet the needs of CALD people with disability in their local communities throughout all of Australia. This will allow them to:**
 - **Facilitate and deliver disability advocacy, in all its forms, to CALD communities; a particular emphasis should be placed on self-advocacy, peer-advocacy and community advocacy programming.**
 - **Engage in relationship building and outreach with CALD communities, creating awareness around the services disability advocacy organisations can provide i.e. to**

directly target CALD communities in an effort to promote access into disability advocacy services/programs.

- **Ensure that all advocacy services are culturally respectful, inclusive and responsive (e.g. meeting the disability, cultural, religious, language and communication needs of CALD people with disability)**
- **Engage in stakeholder networking and relationship building to link with local disability and/or multicultural services and organisations and communities to 1) better support CALD people with disability, and 2) work to remove the barriers CALD people with disability currently face and thus promote social, economic and cultural inclusion of CALD people with disability.**

5.2.4 People with disability in rural, regional and remote locations

There is likely to be less choice and availability of independent advocacy in rural, regional and remote locations. A focus on cross disability advocacy that is responsive to individual needs and circumstances is critical in this situation.

Delivering advocacy support to people with disability in these locations requires a significant amount of outreach in terms of travelling to towns and communities within particular areas. It cannot be expected that people with disability are able to travel to an office in another location. Independent advocacy organisations should also focus on building relationships and linkages within and across communities to build trust, ensure information about independent advocacy is shared, and in order to establish collaborative working relationships with other support organisations to maximise the benefit of outreach support. In certain circumstances and if available for the person with disability or the community, technology could provide an additional communication and access tool for people with disability.

Formal partnership models for the support and delivery of independent advocacy in rural, regional and remote locations should be resourced and encouraged. For example, PWDA has established an Australian Remote Disability Advocacy Network that focuses on practice issues in relation to providing advocacy support to remote communities. The network focuses exclusively on outreach and engagement with Aboriginal and Torres Strait Islander people with disability, and is also able to provide a platform for systemic issues emerging from remote communities. The network involves PWDA regional advocates in Mt Isa, advocates in Alice Springs and Tennant Creek, advocates in Broome, Fitzroy Crossing and Carnarvon, NPY Women's Council and Darwin Community Legal Service. FPDN are linked into this network. There are challenges in maintaining this network as there are no additional resources for this partnership role.

The ACDA recommends that a reformed NDAP values and resources outreach and engagement and partnership approaches and models to strengthen independent advocacy support to people with disability in rural, regional and remote locations.

5.2.5 People who are very socially isolated including those with communication difficulties and those in institutional care?

Many people with disability are not connected to the disability community or disability support system, have no family and / or live on 'the fringes' of our communities. For example, people who are in frequent contact with the criminal justice system, who are homeless, who live in segregated supported accommodation environments (boarding / rooming houses, group homes and large

residential centres). For many of these people, there is a myriad of complex issues and barriers that have remained unaddressed for many years. Others may also not identify as having disability.

It is critical that outreach and engagement strategies underpin independent advocacy for these groups of people. Outreach and engagement enables advocates to build relationships and trust over time, understand more fully the situation and needs of the person and provide appropriate advocacy support. Outreach and engagement can take more time and effort in terms of achieving advocacy outcomes and this needs to be recognised and valued.

For example, PWDA is funded by the NSW Government to provide group advocacy for residents of licensed boarding houses in NSW. This is largely an outreach and engagement approach to ongoing 'visiting' of licensed boarding houses and building trusted relationships with residents in order to provide advocacy support. This trust has benefited the residents in other ways, as PWDA has also been able to provide training and support on human rights, violence and relationships and tenancy rights to the residents. In the NDIS Hunter trial site, PWDA has also formed a peer support or self-advocacy group of boarding house residents that is closely connected to our advocacy (both individual and systemic), training and information functions.

For independent advocacy to be able to do outreach and engagement, particularly in institutional care settings, there often needs to be cooperation from the management and / or funding body of the facility. In some cases, advocates have been refused permission to enter premises effectively denying people with disability access to independent advocacy. There needs to be a mechanism or process in NDAP that enables advocates to report refusal of entry to facilities, and for DSS to address this with the facility owner or funding body.

It is unclear what is specifically meant by 'communication difficulties' in this question. The communication needs of each individual with disability will vary and will require appropriate response from independent advocacy, such as the provision of sign language interpreters, tactile interpreters, communication boards and augmentative communication devices. Sometimes communication can only occur after trust has been built with the person.

Expertise in communicating with people with disability needs to be part of the competency within the independent advocacy sector, including working with communication support workers or trusted family members and other support workers, and using supported decision making principles and processes that assist in understanding a person's will and preferences.

The ACDA recommends:

- **that a reformed NDAP values and resources a concerted outreach and engagement approach to independent advocacy for people who are socially isolated.**
- **that DSS consult with independent advocacy to develop mechanisms and processes to address 'refusal of entry' issues for independent advocacy.**
- **that competency in communicating with people with disability, including using supported decision making principles and processes are integral to the delivery of independent advocacy.**

5.3 Improving the advocacy evidence base and coordination on systemic issues

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

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?*

NDAP is a critical, interconnected component of progressing the human rights of people with disability and supporting implementation of Australia's international human rights obligations. This means that the evidence base for independent advocacy needs to be underpinned by a nationally consistent disaggregated data collection system that can be used to assess progress in meeting human rights outcomes for people with disability, including for people with disability from specific population groups.

DPOs and independent advocacy organisations should be able to share and examine the qualitative and quantitative data from NDAP and other program sources to strengthen the human rights evidence base and identify emerging human rights issues. All Australian governments should be able to use NDAP data to measure compliance and progress and to report on implementing the NDS and other national action plans (such as the National Plan to Prevent Violence against Women and Their Children and Closing the Gap), and compliance and progress and to report to the UN on their international human rights obligations.

The NDAP data and evidence base needs to be publically available. This would enable DPOs and human rights advocates, including those within the disability, women's, multicultural, Indigenous, LGBTIQ sectors to identify and prioritise systemic issues for people with disability. This would assist in promoting collaboration within and across human rights advocacy as well as within and across government agendas, plans and policy development.

The advocacy sector support structure, recommended in this submission under section 3.2 should have a central, coordinating role across the disability and broader human rights advocacy sector in making NDAP data publically available through online and other means, including the production of independent annual report cards on the status of human rights for people with disability.³⁹

Many DPOs and independent advocacy organisations at both State, Territory and Commonwealth levels work with a wide range of government bodies and non-government organisations on systemic issues. There are also some State based independent advocacy coordinating points⁴⁰ that discuss emerging systemic issues. The coordination role of the advocacy sector support structure should also assist in identifying critical systemic issues for collaborative systemic advocacy across the broader human rights advocacy sector, assist governments in setting policy

³⁹ See e.g., the National Report Cards produced by the National Mental Health Commission

⁴⁰ For example, NSW Disability Advocacy Network, NSW Disability Network Forum, and Combined Advocacy Group QLD

development and law reform agendas, and assist human rights and complaints bodies, such as the Australian Human Rights Commission and Ombudsman organisations to prioritise strategic work and activities.

The ACDA recommends that:

- **A reformed NDAP must as a priority, establish a baseline of human rights based disaggregated data against which future progress towards compliance with the UN treaties (to which Australia is a party) can be measured and monitored.**
- **The advocacy sector support structure coordinate the public availability of NDAP data for the human rights advocacy sector, including the preparation of independent annual report cards on the status of human rights for people with disability.**
- **The advocacy sector support structure collaborate with State and Territory systemic advocacy organisations and coordinating points to strengthen collaborative systemic advocacy priorities and activities across a broad range of government and non-government organisations.**

5.4 The interface with the NDIS and addressing conflict of interest

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

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

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

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, the ACDA welcomes the decision for NDAP to “be funded and run independently of the NDIS”.⁴¹

However, it is also critical to recognise that DPOs and many independent advocacy organisations already undertake, and have significant expertise in functions, programs and activities that constitute Information, Linkages and Capacity Building (ILC) support, or that lend themselves to the provision of other aspects of NDIS services. Investment in the existing expertise within the DPO and independent advocacy sector is more efficient than ‘reinventing the wheel’, but addressing conflict of interest is critical in this regard.

DPOs and independent advocacy organisations have a high level of awareness regarding conflicts of interest and have a number of systems in place to address conflicts of interest within governance structures and the design and delivery of activities. In addition, NDAP funded organisations are required to be independently certified under a Quality Assurance process that audits organisations against the National Standards for Disability Services. The audit includes a strong focus on demonstrating management of conflicts of interests in governance, operations and the delivery of activities.

However, in the new and evolving NDIS environment, it is essential that more expertise in relation to managing conflicts of interest is obtained, in conjunction with collaborative work and

⁴¹ Department of Social Services, ‘Review of the National Disability Advocacy Program Discussion Paper’, April 2016, p.5

consultation with DPOs and independent advocacy organisations to ensure that conflicts of interest are avoided.

The ACDA recommends that DSS and the NDIA conduct a targeted forum with DPOs and independent advocacy organisations to examine conflicts of interest and possible mechanisms, policies and funding requirements that can address conflicts that arise at the interface between NDAP funded activities and the NDIS.

5.5 Understanding and improving access to justice

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

What barriers prevent people with disability from accessing justice?

What models of legal advocacy are most effective?

The over representation of people with disability in the justice system, the indefinite detention of unconvicted people with disability in prisons and the significant barriers to access to justice for people with disability are now well-known, and have been identified in recent reports from the Australian Human Rights Commission, the Australian Law Reform Commission and the Productivity Commission,⁴² and the subject of inquiry, including the current Senate Standing Committee on Community Affairs Inquiry into Indefinite Detention of of people with cognitive and psychiatric impairment in Australia.⁴³ Significant access to justice barriers have been identified in the ability of victims to seek legal redress for violence, abuse and neglect.⁴⁴

This concerning human rights situation means that there is significant demand for systemic and legal advocacy to focus on human rights reform of policy and legislative frameworks across all State and Territory jurisdictions and at the national level.

There is also significant demand for advocacy support for individuals in contact with the criminal justice system, to navigate legal processes and systems, to participate in guardianship, financial management and mental health tribunals, in child protection and the removal of children, to make complaints and participate in complaints handling processes and to obtain legal assistance for a range of matters, such as credit and tenancy related issues.

DPOs and independent advocacy organisations provide legal advocacy at the individual and systemic level. However, specific legal practitioners are based in legal advocacy centres, including the very few NDAP funded legal advocacy centres. This means that DPOs and independent advocacy organisations utilise, or should utilise networks and links with community legal centres, including disability discrimination legal centres, disability specific legal centres and pro bono law firms to obtain legal practitioner expertise. However, this is becoming increasingly difficult as funding cuts to legal aid and community legal centres has severely limited the legal expertise that

⁴² Australian Human Rights Commission, *Equal before the Law: Towards disability justice strategies*, 2014; Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, ALRC Report 124, 2014; Productivity Commission, Australian Government, *Access to Justice Arrangements – Draft Report*, 2014.

⁴³ <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Indefinite_Detention>

⁴⁴ Final report from the Senate Standing Committee on Community Affairs Inquiry into violence, abuse and neglect against people with disability
<http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report>

can be provided, and this has increased demand for legal advocacy from DPOs and independent advocacy.

In addition, there is often a lack of legal expertise in working with people with disability in generalist legal centres, and often the role of independent advocacy is to work with these centres to ensure people with disability receive the legal support they need. This means that people with disability often need both non-legal advocacy support as well as specific legal assistance to resolve legal matters.

While a reformed NDAP should increase investment in all forms of legal advocacy, there needs to be considerable focus and investment on access to justice for people with disability from other areas of government, such as the Attorney General's Department and equivalent State and Territory based agencies, and within national plans and strategies.

The ACDA recommends that:

- **The Australian Government act on the recommendations from recent reports and inquiries, including by incorporating recommendations into the National Disability Strategy, to ensure action is taken to address violations of human rights experienced by people with disability in accessing justice.**
- **DSS and the Attorney General's Department work in partnership with DPOs and independent advocacy organisations to examine good practice models⁴⁵ of specialist legal advocacy, coordinate the delivery of legal advocacy for people with disability across funding streams and service sectors, and facilitate reinvestment in the community legal sector and in legal aid to address the significant access to justice issues facing people with disability.**
- **A reformed NDAP must resource disability specialist legal centres within each State and Territory and at the national level that are able to provide specialist legal assistance to all people with disability.**
- **The recommendations to address the significant human rights violations faced by Aboriginal and Torres Strait Islander people in relation to access to justice, as discussed in this submission in section 5.2.2, are actioned in a reformed NDAP.**



⁴⁵ For example, the Criminal Justice Support Network conducted by the Intellectual Disability Rights Service in NSW.