

Response to National Disability Advocacy Framework

8th July 2022

Background

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council is an Aboriginal led and controlled organisation whose membership is drawn from the remote NPY Lands in the Central Australian cross-border region (the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands, or NPY Lands). The Anangu (Aboriginal people) of the NPY Lands are closely connected to their traditional culture, family and country. This submission focuses on issues that Anangu with disability, their families and NPY staff who have decades of experience supporting people living on the APY and NPY lands.

The NPY Lands consist of 25 very remote communities and homelands, spread across 350,000 square kilometres of semi-arid country. The communities are geographically remote, usually reached by unsealed roads, which are subject to closures for cultural activities and wet weather damage. The total population of the region is around 6000, with an average of around 200 in each community. These communities have limited access to goods and services; typically, there is a single store, a clinic, a school, and a community office. Regional service centres are located in Alice Springs, Kalgoorlie and Port Augusta at distances between 300 and 1500 kilometres. There are few service providers either based on or visiting the Lands.

Anangu with disabilities have consistently expressed their desire to live on the Lands; they want to live on country with family and culture. This was confirmed in research carried out by NPYWC in conjunction with Sydney and Flinders Universities, and reported on in *Walykumunu Nyinaratjaku (To Live a Good Life)*¹ and *Tjitji Atunymankupai Walytja Tjutangku (Looking after children with disabilities from the NPY Lands)*². In that, research Anangu with disabilities were clear that they wanted to stay on the Lands. This was more important to them than the quality of care, or of the lack of services, they might experience.

¹ <http://www.npywc.org.au/wp-content/uploads/Walykumunu-Nyinaratjaku-October-2018.pdf>

² <https://www.npywc.org.au/wp-content/uploads/Children-with-disability-in-the-NPY-Lands-Tjitji-Atunymankupai.pdf>

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This choice was again expressed more recently when NPY consulted with people living on the Lands as part of a submission to the NT Disability Strategy³

1. Do you believe the new NDAF encompasses your vision of advocacy? If not, what changes are required?

Some key issues should be identified and embedded as foundational in the provision of advocacy.

- Advocacy can never be a fee for service program
- Advocacy is not a substitute for case management
- Advocacy cannot be time limited
- To improve the lives of people with disabilities individual advocacy must be linked directly to systemic advocacy. This will contribute to effective change and ensure systematic priorities are valid
- Funding for advocacy should include and be directed to specific cohorts to ensure equity and that 'no one is left behind'
- Advocacy for remote aboriginal communities should predominately be delivered face to face.
- Advocates should operate and engage within a 'community development framework⁴' as this will contribute to outcomes that strengthen communities and advance employment opportunities; such as building a rights knowledge base, skills development and supporting engagement with decision making processes
- Advocacy programs should include support for mentoring of emerging community advocates and peer to peer advocacy training
- Implementation of advocacy in remote communities should be in line with 'Closing The Gap' framework and principles

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

- In general, NDIS Plans developed for people living in remote communities do not genuinely reflect their needs and/or what services they can access. The New South Wales Council for Intellectual Disability identified "*where available, advocacy has resulted in better plans and packages for scheme participants*"⁵;

³ NT National Disability Strategy Consultation <https://haveyoursay.nt.gov.au/nt-disability-strategy>

⁴ Australian Cross Disability Alliance (ACDA) Submission to the Review of the National Disability Advocacy Program Discussion Paper' Prepared by Therese Sands on behalf of the Australian Cross Disability Alliance. © Australian Cross Disability Alliance (ACDA) June 2016

⁵ Chapter 9 National Disability Insurance Scheme
https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report/c09

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this reveals the need for more advocacy within NDIS processes. Conversely the statement by the Commonwealth Ombudsman that “...others entering the scheme without the benefit of advocacy may not receive the most beneficial plan. This may be simply because they do not fully appreciate the range of choices that are available to them including the opportunity to think about goals (rather than only needs), or feel unable to clearly articulate the types and amounts of supports they should be entitled to access”⁶ reveals the need for people with disabilities to have a better understanding of NDIS Plans and the need for independent advocacy, this is specifically relevant to people living in remote communities.

- The Principles state that the ‘cultural safety and capabilities of non-Indigenous disability advocacy are strengthened’; for successful growth of all types of advocacy in remote communities ‘trust’ will be a key element towards strengthening capabilities. Services working in remote areas need to develop trust-based relationships. It is only just over 50 years since the indigenous people of Australia were included as part of the voting population and within ‘living memory’ many have experienced removal from their lands, stolen wages and stolen children. The trust level is understandably low. At this time of a rapidly changing disability landscape, it is important not to erode any existing levels of trust. Intentional steps must be seen to be taken to build and maintain trust. For some cohorts, advocacy can be successfully provided by organisations who have already developed trusting relationships and have a deep understanding of the issues affecting people with disability living in remote communities. Independent advocacy is important however, people living with disabilities in remote communities have consistently expressed that they want to work with people & organisations that they know and trust. They are unlikely to engage with strangers. The trust element must be included in any analysis of services and is essential to developing successful advocacy services in remote communities.
- The NDIS aims to transform how people with disabilities receive both mainstream and specialist services, this includes mainstream health delivery. There is an urgent need for improved clarification between NDIA/NDIS and health services at the local, state and national level. It is common for there to be confusion when people with disabilities and health services interact; health workers often assume that everything will be covered by the NDIS, or that everyone with a disability receives NDIS funding. For people with disabilities

⁶ Review of the National Disability Advocacy Framework COMMONWEALTH OMBUDSMAN 24 July 2015 <https://engage.dss.gov.au/wp-content/uploads/2015/07/Submission-to-NDAF-review-July2015.pdf>

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living in remote aboriginal communities the PATS (Patient Assisted Transport Scheme) is in urgent need of reform and a clarification of PATS responsibilities to all citizens including people with disabilities.

3. Are the outcomes of the NDAF clear and achievable? Should different ones be included? If so, what should be included?

- A genuine commitment to actions will be required if NDAF outcomes are to be realised for Anangu with disabilities living in remote Australia. It is unarguable that the current levels of poverty for aboriginals living in remote communities is unacceptable and people with disabilities in those communities are generally more severely impacted. Without the basic needs of food, bedding, bathing being met, it is unrealistic to expect people to prioritise engagement with the broader aims of the NDAF. Participation in design, decision-making, implementation and evaluation processes requires the capacity for a level of sustained commitment and access to relevant information. Policies and programs, which are most often conceived thousands of miles from these communities, rarely identify the impact that poverty has on implementation. In addition to the impact that unmet needs have on a community or individual's capacity to maximise their engagement with and participation in programs the trust deficit is also a mitigating factor. It is important to throw a light on these deep societal and political realities before considering how advocacy can be most effective towards improving the lives of pwd living in remote Australia.

4. Are the responsibilities, reform and policy directions of the NDAF relevant or should different ones be included?

There will be an increased demand for all forms of advocacy, and increased need for disability advocates to acquire new and broader expertise as people will be needing advocates across a range of sectors. The oversight of policy and program failures in the mainstream cannot be left to a small cohort of advocates. Advocates capacity for pursuing policy failure is limited. As indicated by the two reports referred to below having clear lines of responsibility is essential and recognised authoritative oversight responsible for such monitoring. A lack of oversight & monitoring systems or processes will reduce the effectiveness of advocacy.

- The “World Report on Disability”⁷ identifies the importance of governments having mechanisms in place that “make it clear where the responsibility lies

⁷ World Report on Disability WHO & World Bank Recommendation #3 2011
<https://www.refworld.org/pdfid/50854a322.pdf>

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for coordination, decision-making, regular monitoring and reporting, and control of resources.”

- The inquiry ‘Services in Remote Communities’ highlighted that ‘Human services’ should be making a greater contribution to improving the wellbeing of Indigenous people living in remote communities. Importantly it noted that although governments may have *“articulated high-level objectives for improving Indigenous outcomes, they do not have a clear vision of what they are trying to achieve at a community level. They have not invested enough in developing an understanding of the needs and existing service levels in communities, or a common set of outcomes that governments and providers can work toward in service provision.”*⁸

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

- The introduction of a ‘market based’ approach via the NDIS has grown the number of for-profit businesses and not-for-profit organisations; which can be good for choice and improved services; however for Anangu communities a competitive market may expose them to exploitation. The ongoing effects of colonisation, language barriers, and limited experience with contracts/agreements they may sign documents because they feel pressured or enticed or not be familiar with English language and concepts. It can be reasonably be predicted that until the ‘market’ settles and people understand it better there will need for advocacy around these issues, however it may be that this will become more complex than advocates can undertake and it would be wise for the NDAF to be alert to the potential need for stronger oversight/monitoring/advocacy by those responsible; as the rorting of TAFE by private businesses⁹ revealed it is essential that participants and taxpayers are protected from disingenuous players.¹⁰ 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

⁸ Services In Remote Indigenous Communities

<https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/04-human-services-reforms-indigenous.pdf>

⁹ “Hundreds of Millions Lost from Vocational Scheme” SMH Farrah Tomazin 7/12/2019

<https://www.smh.com.au/politics/federal/hundreds-of-millions-lost-from-vocational-scheme-20191206-p53hqk.html>

¹⁰ 4.3.2 ‘Australian Cross Disability Alliance (ACDA) Submission to the Review of the National Disability Advocacy Program Discussion Paper’ Prepared by Therese Sands on behalf of the Australian Cross Disability Alliance. © Australian Cross Disability Alliance (ACDA) June 2016

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- NDAF should provide funding and support for specialist advocacy services that support the rights of people with disabilities in the prison system and through the release process. There is a desperate need for the justice sector including police and the prison workforce to be provided with disability training and for people held in the justice system to be provided with quality information and specialist advocacy; this is in addition and separate from legal advocacy. The NDAF should be proactive in addressing the indefensible over representation of people with cognitive disabilities within the justice system.

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

The NT has an over-representation of aboriginal people under guardianship orders this needs to be addressed; we support the development of program as suggested by NAAJA ¹¹

¹¹ https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report/c07