Ngaanyatjarra
Pitjantjatjara
Yankunytjatjara
Women's Council

Ngaanyatjarra Yankunytjatjara Pitjantjatjara Women's Council (Aboriginal Corporation)

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with Disability

September 2020

Summary

Current Situation

Anangu (Aboriginal people from the NPY Lands) society in remote communities has its own traditional culture, lifestyle and language. Anangu with disability have clearly stated that they want to continue living on their traditional country with family and culture. Rates of disability are at least twice those of mainstream Australia. Poverty is endemic in remote communities and there is competition for basic resources, particularly food, bedding and clothing. This can lead to abuse and or neglect of vulnerable people including those with disability, a situation which has become accepted and is generally considered normal. The poverty in remote communities focusses Anangu (both carers and people with disability) on their immediate needs rather than investing time in things that may be of benefit in the future such as therapy services.

Services are basic on community, with medical and allied health specialists visiting for "fly in fly out" visits or not at all. Both ongoing therapeutic support programs and day-to-day support workers are limited or not available in most communities. Prescription and provision of assistive technology is subject to long delays as are maintenance and repairs. Equipment that people with disabilities have is not always the most appropriate for the challenges of the remote environment. Buildings and public transport vehicles are often not disability accessible.

Anangu do not always understand the beneficial role of therapeutic programs and as a result do not engage with them. They do not plan for the future. Very few workers on the Lands receive cultural orientation that is guided by Anangu, or have the flexibility to adapt to the way Anangu want them to work.

People with disability with high support needs are removed from the Lands into institutional care because of the lack of day-to-day support available on the Lands. Family members cannot come and stay with them. People rarely have the opportunity to visit their homelands (reverse respite). Children who are removed lose contact with family, country and culture.

The National Disability Insurance Scheme(NDIS) takes little or no account of people's lifestyles and their background. Plans are written in English, in language that is incomprehensible to Anangu, whose culture is oral. Goals do not reflect people's desire for access to basic needs, and often ask for services that are unavailable in remote communities. There is excessive and complex paperwork for clients to sign.

Possible ways forward

Maintaining current higher levels of Centrelink assistance would help reduce the universal poverty in communities. Ongoing education regarding human rights will start to increase the awareness of and concern about abuse within communities.

The establishment of a disability support workforce and funding through Direct Commissioning (block funding arrangements) the required extensive and ongoing support and supervision of the workforce would assist Anangu with a disability to live a better life, and would mean less people needing to be accommodated in institutions and being removed from the Lands.

There is a need for appropriate, staffed disability accommodation on the Lands. This might also be used for reverse respite for An̲angu of all ages who have been moved off the Lands. All An̲angu who have been moved off the Lands need funding to visit the Lands regularly.

There is a need for therapists based on the Lands, or undertaking extensive visits. They could train and support local workers to assist with therapy and care of An̲angu with a disability.

There is a need to train and supervise people in communities through Direct Commissioning to do the maintenance and repair of mobility equipment.

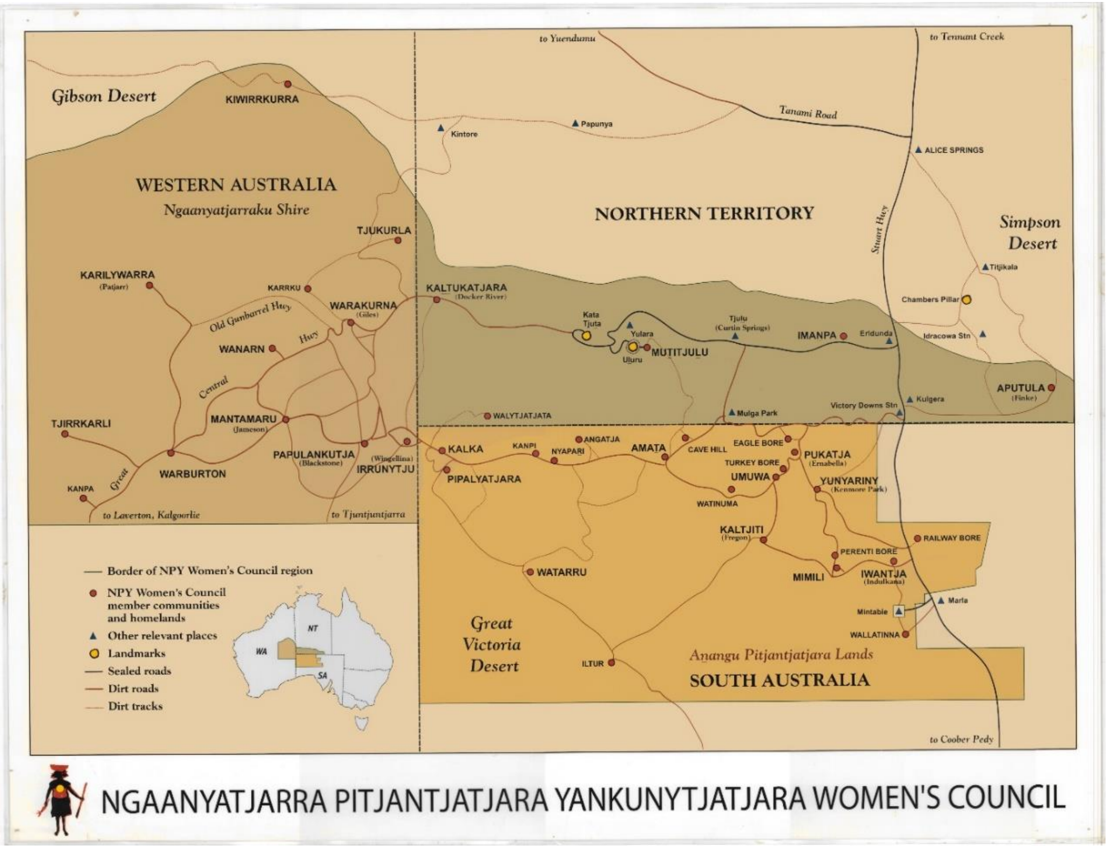
Buildings and transport vehicles need to be disability accessible.

Increased and ongoing support and advocacy for An̲angu to help with issues including the NDIS processes, weighing up the benefits of alternative sources of support, and having NDIS plans that reflect people's desires. An̲angu also need advocacy and assistance to maintain contact with their children with disability who have been moved off the Lands.

Funding is needed for people with disability who are not eligible for an NDIS Plan. There needs to be funding available to support people with disability who are unable to meet the threshold for NDIS eligibility or those who choose not to engage with NDIS. In order to support An̲angu to continue living on country and to ensure carer well-being it is imperative that there are sources of funding available to support people with disability who don't have an NDIS Plan but want to continue living on country with their families. The ability to access regular respite and other practical support can be critical for maintaining people in the caring role.

Background

Anangu (Aboriginal people from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands) in remote Central Australia live in poverty in an extreme environment. The climate is harsh, and communities are isolated, generally 50 to 150 kilometres apart, separated by dirt roads which are variable in condition at the best of times and are regularly closed because of rain or for cultural reasons. Communities are small – Warburton, in WA and Ernabella, SA are the largest with a population of around 600, while some others have less than a hundred residents, and some people live in even smaller homelands or outstations.



All communities have limited access to goods and services, typically being served by a single store, a primary health clinic, a school, and a community office. Regional service centres are located in Alice Springs (Northern Territory), Kalgoorlie (Western Australia), and Port Augusta (South Australia), at distances of between 300 and 1500 kilometres from communities.

There are a number of systemic issues which affect people with disability living in the remote NPY communities. Foremost is the high level of poverty in remote communities, with Anangu concerned about where the next meal is coming from, or where to sleep at night. Most government and service provider based systems for helping people with a disability do not take account of the different lifestyle and needs of Anangu with a disability, despite paying lip service to offering a "person-centred' service. This exacerbates issues related both to the endemic poverty and also to the traditional culture and lifestyle of people in this region: the way they view life, bringing up children, illness and disability and social and familial responsibility. One effect of the prevalence of some of the abuses described below is that these have become normalised, and are seen by Anangu as a part of everyday life and relationships.

Poverty

Because of the high levels of poverty in the Lands, people are driven by basic needs for food, shelter and safety. They are competing for limited resources, and the more vulnerable, such as those who have a disability, often lose out. An elderly woman commented, '*People are fighting over food in that house*'. Another woman commented that her son with an acquired brain injury '*has stones thrown at him*' by children in the community. Several of our disability clients who are living with an acquired brain injury need protection from family and community members who take their money, or utilise money sent directly to the community store on behalf of the client. The person with a disability is then left with no food and no possibility of buying any. When they are upset, and possibly become angry or violent at the store's refusal to give them food or cigarettes, the store may well refuse to serve that person in future.

The lack of resources is exacerbated by the prevalent cultural tradition practice of sharing, which dictates that any goods or money held by one family member shall be used for the good of the family in accordance with established priorities which may or may not include the family member who has the goods or money. This makes it difficult, and often impossible for the person with a disability to have a say in the use of any money given to them. It also makes it extremely difficult for people with a disability to refuse to contribute their money, goods or food to certain family members. In addition, this traditional practice may be abused by family members in need.

One of our clients, living in community, was unable to access her own money from her bank account because of the security measures placed on her account by the bank due to frequent instances of family members (and particularly her sister) taking her money. However, her sister walked into a bank in a regional centre with a statutory declaration saying she was the client and removed all the funds that had accumulated. The bank has indicated that the funds cannot be returned to the client unless she reports her sister to the police, an act which would be totally culturally unacceptable.

During the recent pandemic, the increased financial income support from Centrelink has significantly reduced the number of requests received by NPY Women's Council for help with food. Maintaining this level of payment would therefore be a good first step towards reducing the level of poverty in remote communities. According to the regional profile for the NPY Lands Empowered Communities Region prepared by the Information and Evaluation Branch, Department of the Prime Minister and Cabinet, the mainstream employment rate for people in the NPY Lands was under 20% in 2011, and would be even lower for people with a disability, so that increasing the levels of income support is an immediate and effective tool for reducing poverty and therefore some of the pressures experienced by the more vulnerable members of the society.

Living in the present

Partly as a consequence of the necessity to satisfy basic life needs, and partly as a result of cultural tradition, A<u>n</u>angu live in the present moment, not considering consequences or planning for the long term. A<u>n</u>angu are very concrete thinkers, with their strength being in the practical and the present. Their language does not include 'either…or'. This limits planning and/or budgeting at all levels- from over the next few days (food and cash budgeting), to the medium term (visits to medical services etc.) to planning for their own and their children's futures. Family members (including children) with disability may not receive the most appropriate therapy or medical attention as a result. A<u>n</u>angu responding to immediate needs or issues will frequently ignore appointments that have been made for them or for a family member with disability to travel to Alice Springs or Perth for an operation or other specialist visit. Family is unlikely to supervise children performing exercises which may have been prescribed for them. One of our adult clients who had experienced a stroke received extensive rehabilitation while in Alice Springs. She was potentially able to regain the ability to walk, but refused to continue with any of the exercises she had learned when she returned to community and has been in a wheelchair ever since.

Availability of services

Therapeutic and specialist services
Services are limited on the NPY Lands. A minimal range of therapeutic services is available to people with a disability on a 'fly in fly out' basis, which in effect means that some service providers such as occupational therapists visit the community once every few months. There is no ongoing support available, so support is often limited to the provision of assistive technology, rather than to offering supported exercise or education programs in the use of, for example, communication devices. Despite the lack of services available in the Lands, many A<u>n</u>angu with disability have NDIS plans providing funds for services which are unavailable, such as social skills development and support, transport, behaviour support and early childhood intervention.

The lack of community-based service provision and mid- to long- term support means that programs such as behaviour modification programs, where effectiveness is only possible through implementation in a person's home environment, are not available. There are currently no such programs operating in the NPY Lands, although they are needed, as evidenced by the number of referrals for this sort of program in people's NDIS plans. Over a quarter of the plans where we provide Coordination of Supports refer to behavioural self-regulation in the participants' goals. Another large fraction of participants' plans includes a goal of improving people's communication skills. Carrying this out effectively would involve education, training and support by Lands-based workers. As is discussed below, Anangu NDIS participants are unlikely to be aware of what is involved in the idea of these programs when agreeing to undertake them. One 58 year old man's plan, specifying *improvement in communication in all environments*, goes on to include this goal, which is clearly not a goal expressed by the participant, but rather is assumed by the NDIS Planner:

> *I will attend the speech therapies and reviews and practice the training. I will learn how to read and write and be confident in dealing with government and non-government agencies such as Centrelink and the bank.*

There are numerous challenges with the provision of assistive technology to Anangu with a disability related to the isolation of remote communities and to the lack of services. Lengthy time frames are involved in having equipment prescribed (awaiting the arrival of a suitably qualified practitioner in community) and in repairing and maintaining equipment, which may have to be sent to a regional centre. Trialling of equipment and ongoing training in the use of equipment is not possible on a "fly in fly out" basis, so Anangu may not receive the maximum benefit from their assistive technology. Some equipment supplied is inappropriate for the terrain which can be soft sand, rock or mud all within a short distance. As people live outdoors much of the time, equipment needs to be sturdier than might be the case in an urban environment. Alleviating these issues requires appropriate levels of funding in people's NDIS plans, as well as working to increase the presence of therapists on the Lands.

There would also be merit in having someone in the local community trained and able to do basic maintenance and repairs on mobility equipment. Because of the low numbers of people in community, and the high cost of infrastructure, including backup and supervision for such a person, this service would need to be funded separately through Direct Commissioning (block funding or similar) arrangements to be viable in remote communities

There are currently no diagnostic services on the NPY Lands for Acquired Brain Injury or Foetal Alcohol Syndrome. Both conditions are common. Diagnosis of these and other conditions is additionally hindered by the lack of culture- and language- appropriate tools.

Specialist appointments
Because there are limited services available in the Lands, people are required to travel long distances to appointments, and stay in places such as Alice Springs or Perth, where they are generally accommodated at Aboriginal hostels. Sometimes a family support person is sent into town with them. Recently, a client was sent in to Alice Springs without her powered wheelchair, and consequently was extremely distressed as, in town, she likes to move around and to visit different places.

The time and effort involved in travel, combined with the necessity of responding to pressing current needs, means that many people miss such specialist appointments, both for themselves and for their children.

Funding is needed to support the expansion of specialist and therapeutic services into the Lands sufficiently to offer Lands-based services to Anangu with disability. A model where workers are located in a particular community and travel to other nearby communities would enable increased services and support to be offered to people with disability. It would require investment not only in workers but in the supportive infrastructure for them, including cultural orientation, housing, vehicles, support and supervision. Without this, many Anangu with disability are deprived of the opportunity to maximise their participation in culture and family life.

Disability Support Workers
Many of the issues raised above would be ameliorated if there were more therapeutic workers available in community. An alternative option could involve therapists working with and overseeing a disability support

workforce, supporting them in appropriate ways to help Aṉangu with disability. However, there are no disability support workers in most communities in the NPY Lands. Some daily care support is currently offered through the Department of Human Services (DHS) in the APY Lands of South Australia, but the Department has indicated it intends to leave the Lands next year.

Because of the lack of disability support workers, people with disability who remain living on the Lands may receive low levels of care or be neglected by family carers, many of whom have a number of other stresses in their daily lives. As an example, an elderly woman who had had a stroke and returned home to her community was on occasion left by family carers in a urine-soaked bed.

People with disabilities are often unable to participate in cultural and community activities such as attending sorry camps and funerals, visiting family or going to football carnivals due to their need for appropriate transport and support.

One of the major consequences of the lack of support workers is that many people have been removed from the Lands and are living in facilities in towns and cities. While there are three aged-care facilities on the NPY Lands (one each in SA, NT and WA), they do not have the capacity to provide high-needs care for elderly people who may have a disability. There is no accommodation on the Lands for younger people who have a disability.

Despite these issues, Aṉangu want to stay on the Lands, with country, family and culture. This was confirmed in the research carried out by the NPYWC in conjunction with Sydney and Flinders Universities, Walykumunu Nyinaratjaku (To Live a Good Life) and Tjitji Atunymankupai Walytja Tjutangku (Looking after children with disabilities from the NPY Lands). In that research people with disabilities were clear that they wanted to stay on the Lands, regardless of the quality of care, or of the lack of services they might experience. The woman referred to above was adamant that she wanted to stay living in community despite her family's neglect, but was deemed by service providers to be unable to make appropriate decisions in her own best interests and was eventually removed against her wishes to an aged care facility.

Building a local workforce

One approach to the lack of support workers on the NPY Lands would involve building up a local workforce. There are a number of barriers to employing local people as carers, including a lack of acculturation into mainstream employment models, concern around payback if the person being cared for becomes sick or dies, high levels of mobility, prioritisation of family and cultural obligations over employment, and concerns about privacy on the part of the family of the person with a disability. While there have been initial projects in each of the three States of the NPY Lands to start developing such a workforce, there has been no follow-up funding. Employing community members as personal care workers is a long-term process. Building peoples' capacity and capability to undertake disability support work requires gradual and well-supported development. It will entail structured training and ongoing long-term support and supervision, as well as a high degree of flexibility to cater for some of the cultural issues likely to arise.

Children with Disability

Families looking after children with a disability are particularly affected by the lack of support workers on the Lands. There are no in-home support services providing help with bathing, lifting or specialist feeding. Domestic assistance, available in some communities, is only for laundry or a meals-on-wheels style service (for a fee). The only respite options which provide a break for family members looking after a child with high-care needs involve the child travelling off country to an institution in a regional or metropolitan centre. If a grandmother is the primary carer for the child with disability, as is commonly the case, she may have additional stresses related to chronic illness and multiple responsibilities.

The lack of support for people looking after children with high-care needs has led to many children moving away from family and community. Almost a third of the children with disabilities from Aṉangu families who took part in the Tjitji Aṯunymankupai Walytja Tjuṯangku (Looking after children with Disabilities from the NPY Lands) research were living off the NPY Lands, away from family, country and culture.

The Tjitji Aṯunymankupai Walytja Tjuṯangku report records that family contact with children who have left the Lands in this way is sporadic or non-existent. Aṉangu are frequently unable to visit their children because of an inability to negotiate the bureaucratic processes involved, and or because they cannot afford the cost of travel and accommodation. In some cases, in order to ensure better care for the child, they have been required to give up their parental rights. Children who are removed from the Lands lose their culture, including language and family. One of our clients commented that her daughter "*is forgetting who I am*".

Disability accommodation off the Lands

Accommodation provided for people in regional centres who have left the Lands because of a need for services is rarely appropriate for Anangu. Anangu live closely with their extended family members, and isolation from family and country results in hopelessness and depression. The supported living options available for people in regional and metropolitan centres do not allow for family members to come and stay, and the person's funding rarely allows for visits back to community. For Anangu who have limited or no English language, there is the additional stress of living in "a sea of a foreign language". It means they rarely encounter the people, shared memories, language and culture that make life meaningful. The development of alternate models of accommodation allowing visits from family members would make an enormous difference to people's lives. Including funding for visits back to community ('reverse respite') in people's accommodation funding would increase people's sense of belonging and their mental wellbeing. This funding was made available for a client when she moved to a regional centre in Western Australia, but was then removed as a result of government cutbacks, so the client was left extremely distressed, particularly as she could not visit her mother who was terminally ill in community.

The establishment of staffed and well-resourced accommodation for people with disability on the NPY Lands would prevent the need for many people with disability to leave the Lands. It would also provide a place where people who have moved off the Lands because of a lack of support could have reverse respite and catch up with family and culture.

Accessibility

Accessible accommodation and community buildings are not the norm in communities. This is also true of transport and vehicles such as the buses and planes that allow people to travel within and between communities. Anangu live a mobile lifestyle, and move house within a community, or stay in other communities frequently. Some providers are discouraged from arranging housing modifications by the fact that people are likely to move to stay with family in another house or community. The appropriate solution, given the high rates of disability in remote communities (nationally, disability rates for Aboriginal people are at least twice as high as for non-Aboriginal people,) would be for housing authorities to ensure that new buildings on the Lands are built to meet universal housing standards.

Information issues

Anangu hold traditional cultural views of the world and of the causes of illness and disability. They attribute many illnesses and emotional states to harmful elements in the spiritual world. These beliefs are very different from those of most workers on the Lands and can affect their engagement with mainstream care, and the communication of medical and therapeutic messages. As these are deeply held cultural beliefs, introducing people to western ways of treating illness and disability is not as simple as for people who come from a background based in the western medical and clinical model. People need extensive support to undertake activities in which they may have little faith, and a single workshop or "education session" is unlikely to change these views.

People with disability from the NPY Lands are not in a position to give "informed consent". The use of the English language is one barrier. Their first (and often second or third) language is one of the three or more Aboriginal languages used in the NPY Lands and surrounding areas. There are almost no qualified interpreters on the Lands, and payment for interpreters through the NDIA depends on their qualifications. The inflexibility of this system disadvantages Anangu.

People living on the Lands do not understand the role of the NDIS, and in recent workshops have been asking us to explain and keep explaining about the way the NDIS works. The complexity of the NDIA bureaucratic systems means that local people employed as interpreters and cultural brokers (the community connectors concept) will require intensive support and oversight in order to enable them to help potential and current participants to understand the role of the NDIS. They are not receiving this support at a level to help them achieve this aim.

Literacy levels are low among A<u>n</u>angu, and organisations working in the NPY Lands need to take account of this. The NDIA's preferred way of communicating with participants is by letter. The option offered is email. These are both entirely inappropriate for A<u>n</u>angu whose preferred mode of contact is face-to-face

Another barrier is the inability of many A<u>n</u>angu to read and comprehend the forms they are offered, and to understand the binding nature of signing the piece of paper. Theirs is an orally based culture. When A<u>n</u>angu are asked to sign forms such as a consent to release information or an agreement to receive NDIS services, they rarely understand the implications of doing so. They do not understand that in "choosing" a Coordinator of Supports from a list, they cannot continue receiving the services they have been receiving from the other service providers on that list. NPYWC has had numerous phone calls from A<u>n</u>angu wanting assistance and not understanding why they are directed back to their chosen COS. A<u>n</u>angu have a holistic view of life. Therefore they find the way that mainstream systems of assistance for people with disabilities are divided and categorised illogical, inflexible and confusing.

The language used in NDIS documents is complex and inappropriate. For instance, the Access Request Form is 9 pages long and requires people to respond to questions such as:

> *Do you consent to the NDIA collecting your information including from these third parties, for the purposes of determining whether you meet the access requirements for the NDIS and to help develop or implement your NDIS Plan if you become a participant?*

The goals in people's plans are manufactured by the NDIS planner, in conjunction with other providers present at the planning meeting, rather than reflecting what people actually say or want. Many people do not understand what their goals mean. Because A<u>n</u>angu live in the present moment, they have difficulty even with the concept of a plan and of goals. One of our Directors explained:

> *Planning future is a risk, you know. If we plan the future now something will happen, you know, like family passing away, and all that. That's get, hold us down.*
> *But really, you know, in our culture and custom we don't really plan for the future. Wiya (no), nothing. It's something new in our system, you know. We've gotta <u>learn</u> about future.*

The following are examples of such 'manufactured' goals where not only the language but the sentiment is unlikely to be meaningful for the participants.

A fifty-one year old woman in a wheelchair has the goal:

> *I would like support to enable me to make good decisions in my daily life. I will achieve this goal by having a personal mentor who will assist me to make good decisions in my daily life, and to build independent skills and abilities. I will be supported by my Coordinator of Supports to engage a culturally and linguistically appropriate person to assist me.*

A man with an acquired brain injury has this goal under the heading social and community activities:
I would like to visit Yulara very often so that I can stay away from the community for few hours' time, which will improve my thinking ability and reduce self-harm tendency as well as to reduce my depression.

A 17 year old boy who is cognitively impaired (and has no reported behaviours of concern) has the goals:

> *I want to learn to understand and manage my emotions.*
> *I would like to learn strategies to help me develop my concentration skills.*

Goals such as these not only require services that are not available on the Lands, they provide an inappropriate foundation for service providers to work with A<u>n</u>angu under their NDIS plan. Desires expressed by A<u>n</u>angu with disability during the recent research conducted to find out how they wanted to improve their lives were focussed on the here and now, and on practical assistance. People wanted to stay on the Lands with family, country and culture. They wanted practical everyday help such as meals, bedding and respite, and transport to events that are a part of community and cultural life. Because kinship is the central organising principle in the social life of A<u>n</u>angu, they perceived that help needs to include the family of the person with disability. Additionally, in A<u>n</u>angu culture it is considered extremely rude to contradict others, so that, even if they understand a proposal, people may not speak up about what they want. A<u>n</u>angu need advocates who know and understand their needs and concerns and are able to support them in speaking up, or are able to speak up on their behalf.

<u>Cultural Orientation of Disability Workers</u>

Very few organisations working in the NPY Lands offer on-going cultural orientation to their staff. Workers rarely utilise local people as interpreters and cultural brokers, adding to the difficulty of communication between people with disability and service providers. A<u>n</u>angu frequently lament the inability of workers to take the time to stop and '*just sit down and listen to the family, to the patients. If they are saying there is something wrong, then listen and find out*'. A<u>n</u>angu culture focusses on relationships and A<u>n</u>angu with disability and their families want face-to-face contact with workers, and the opportunity to build trusting relationships.

<u>Conclusion</u>

Aboriginal people with disability from the remote communities of the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands experience violence, abuse, neglect and exploitation as a result of a number of complex and interrelated issues. The endemic poverty in remote communities focusses A<u>n</u>angu (both carers and people with disability) on their immediate needs, which can result in neglect and abuse of vulnerable people. Living within their traditional culture and language often makes it difficult for A<u>n</u>angu to understand mainstream approaches to disability and to planning for the future for people with a disability.

Many A<u>n</u>angu are reluctant to engage with services, a situation which is exacerbated by the perception that there is no immediate benefit from engagement, and by the culturally inappropriate ways in which many services work. Funding bodies such as the NDIA do not take account of or make allowances for the remote community situation when they specify how people will work with A<u>n</u>angu with disability. NDIS plans ignore the lack of both specialist and everyday support services on the NPY Lands, and continue to have goals which are inappropriate for and meaningless to A<u>n</u>angu.

Improving support for Anangu with disability
Living on country with family is crucial for the mental health and wellbeing of all A<u>n</u>angu. Because of the normalisation of violence and abuse in A<u>n</u>angu society, there is a need for human rights education in communities. This will need to be an ongoing process aimed at raising awareness of and concern about abuse of vulnerable people, including those with disability.

Despite their need to live on the Lands with family and culture, many A<u>n</u>angu with disability are living off the Lands, away from family, culture and country because of the lack of services and support options in remote communities. Children with disabilities lose contact with their families and gradually lose language and culture, while their families grieve for them.

The establishment of staffed and well-resourced, purpose-built accommodation for people with disability on the NPY Lands would prevent the need for most people with a disability to leave the Lands. It would also provide a place where people who have moved off the Lands because of a lack of support could have respite and catch up with family.

There is a need for consultation with An̲angu around changes to the provision of services and support for Anangu with a disability. In the research referred to above, people asked for services such as domestic help, transport to events in nearby communities and families were concerned about providing support for the activities of daily living. Increased and more flexible services, a range of in-community accommodation options, and the development of a well-supported local workforce are all areas where the situation of An̲angu with disability could be improved. Maintaining current (Covid-19) levels of Centrelink assistance to all An̲angu currently receiving it would be a first step towards reducing the universal poverty in remote communities which is a key factor in the abuse and neglect of Anangu with disability. Building houses and community buildings to accessible standards would eliminate this particular area of discrimination against An̲angu with disability. Because communities in the Lands are distant from each other and from regional centres it would also help An̲angu with a disability to fulfil some of their lifestyle and therapeutic needs if the public transport systems (twice weekly bus and weekly planes to most communities) were disability friendly.

Funding is needed for people with disability who are not eligible for an NDIS Plan. There needs to be funding available to support people with disability who are unable to meet the threshold for NDIS eligibility or those who choose not to engage with NDIS. In order to support An̲angu to continue living on country and to ensure carer well-being it is imperative that there are sources of funding available to support people with disability who don't have an NDIS Plan but want to continue living on country with their families. The ability to access regular respite and other practical support can be critical for maintaining people in the caring role.

Service providers and workers need to undertake on-going cultural orientation, provided by and in consultation with An̲angu, so that workers understand the expectations and constraints perceived by An̲angu, and can adapt the provision of services to better fit the local situation. Workers need to employ An̲angu co-workers in order to achieve good outcomes for everyone concerned. This may include spending time getting to know the clients and the client family to develop good relationships.

An̲angu need advocates to help them understand and negotiate some of the complex bureaucratic processes involved in areas such as developing NDIS plans, assessing whether, for instance, they will benefit more by accepting support from My Aged Care or from the NDIS, and maintaining contact with their children and family members with disability who have been removed from the Lands because of a lack of disability supports.

Advocates need to be people who have built trusting relationships with An̲angu and who listen to their concerns respectfully and can help them speak up or can speak up for them when An̲angu have concerns about service provision.

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