

**Ngaanyatjarra Pitjantjatjara Yankunytjara Women's Council (Aboriginal Corporation)
submission to the Joint Standing Committee on the NDIS Inquiry into NDIS participant
experience in rural, regional and remote Australia**

February 2024

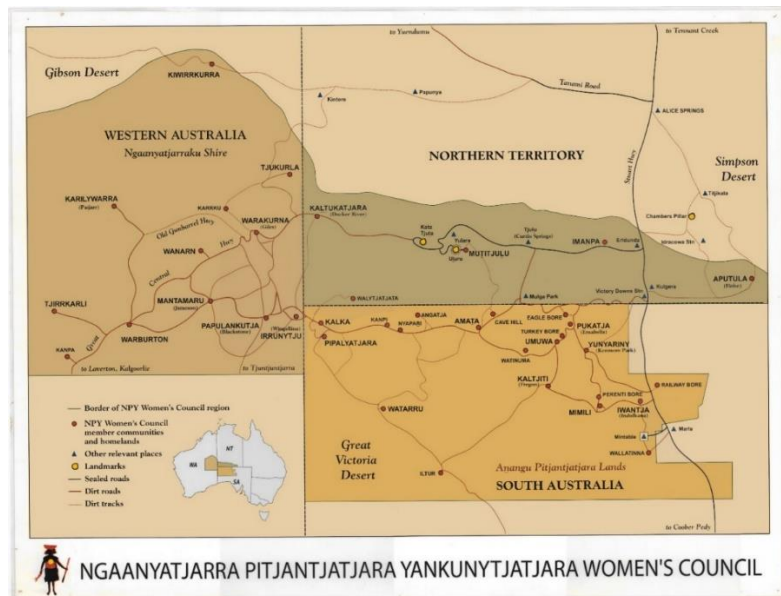
Background

The organisation

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (NPYWC) 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, shown below). The organisation is small to medium sized, and delivers health, social and cultural services to all Anangu, including working with people with disability. The Anangu (Aboriginal people) of the NPY Lands are closely connected to their traditional culture, family and country. This submission focuses on concerns affecting Anangu with disability and their families, particularly with regard to the operation of the NDIS in remote communities.

The situation

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, and almost all are reached by unsealed roads which are subject to closures for cultural activities and wet weather and the resultant damage. The total population of the region is around 6000, with an average community population of around 200. All communities have limited access to goods and services, typically being served by 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 of between 300 and 1500 kilometres. Few service providers operate in the Lands, either based there or visiting regularly.



Life for Anangu in remote communities

Anangu (Aboriginal people from the central Australian cross border region) society in remote communities has its own traditional culture, lifestyle and language. Rates of disability are at least twice those of mainstream Australia. Poverty is endemic throughout these remote communities and there is competition for basic

resources, particularly food, bedding and clothing. Poverty focusses Anangu (both family-based carers and people with disability) on their immediate needs rather than allowing them to invest time in things that may be of benefit in the future such as therapeutic services. Many Anangu do not understand or value the beneficial role of therapeutic programs and as a result do not prioritise or engage with them comfortably.

Anangu with disability have explicitly stated they want to live 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, and reported on in [Walykumunu-Nyinaratjaku-October-2018.pdf \(npywc.org.au\)](#) (To Live a Good Life) and [Children-with-disability-in-the-NPY-Lands-Tjitji-Atunymankupai.pdf \(npywc.org.au\)](#). In that research, people with disabilities were clear that staying on the Lands was more important to them than the quality of care, or the lack of services they might encounter.

Services are basic on community, with medical and allied health specialists visiting for “fly in fly out” visits or not at all. Neither ongoing therapeutic support programs nor day-to-day support workers are available in most communities. Prescription and provision of assistive technology is subject to long delays as are maintenance and repairs. Assistive equipment for people with disabilities is not always the most appropriate for the challenges of the remote environment. Buildings and public transport vehicles are often not disability accessible. 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.

Applying to become an NDIS participant

The Remote Community Connector system

Remote Community Connectors are touted as being the key to NDIS access. However, these roles are not always clearly understood by the people appointed to the positions.

Because of their traditional cultural background, local people employed as interpreters and cultural brokers (community connectors) require intensive support and oversight. They are working from a basis of limited English, literacy skills and bureaucratic experience, and an absence of trusting relationships with the NDIA staff. In this context they struggle to understand the role of the NDIS and the complexity of the bureaucratic systems involved and are therefore unable to help potential and current participants effectively. They are not receiving support at a level to help them achieve this aim. One community connector in WA asked the NPYWC Coordinator of Supports to explain the community connector role to her.

In some cases, the people appointed as community connectors are from off the Lands and do not understand the local Aboriginal languages. They are therefore completely unable to work productively as interpreters or cultural brokers to help the applicant or participant understand the situation. For instance, an NDIA access request submitted in May 2023 through the community connector system received no response. The applicant, a young woman in her twenties, has been diagnosed with TUBB4A related leukodystrophy. She experiences dystonia, choreoathetosis, rigidity, and ataxia. Her access request has been followed up every month, sometimes multiple times. In January 2024, it became clear that no access request had been submitted to the NDIA, and NPYWC submitted one directly to the NDIA.

People employed as community connectors are often also employed as Aboriginal Health Workers in the primary health clinics and prioritise that role over the community connector role. This makes it difficult to access the community connectors as they are busy with other (clinical) teams or carrying out other health worker roles. For instance, the community connectors were asked to help with the men’s program by picking up the service providers who fly in for the program each week, but were unable to prioritise that activity, and this task is therefore performed by NPYWC Coordinator of Supports staff in the interests of maintaining the availability of the program.

One problem with the Primary health/community connector association is that the role appears very different in each of the three States where NPYWC works. One primary health provider has had numerous staff changes and been unable to fill a number of vacancies, and the community connector management has suffered as a result.

Anangu employed as community connectors are likely to experience conflicts of interest in the work that is expected of them. They have established relationships within the community which may include avoidance obligations, negative relationships or family priorities they are expected to comply with. Anangu will only talk about this to a well-trusted worker, if at all, so that in working with the community connectors, staff need to be aware of the likely impact of these relationships.

Further issues relating to NDIS access

Despite defining disability in terms of functional issues, the NDIS requires diagnosis of the impediment underlying the applicant's disability. Often they will not accept occupational therapist reports, but require input from a doctor or specialist

Obtaining a full functional assessment, which is required for NDIS access, can be extremely difficult or impossible. For example, one man applied via the local Aboriginal Health provider for NDIS access. He didn't have a full functional assessment and was refused access. The provider indicated they 'didn't have the capacity' to undertake a full functional assessment in order for him to re-apply. NPYWC offered to pay for his full functional assessment through a local allied health provider but was told there would be up to a one year wait. NPYWC is now pursuing other possible occupational therapists to conduct the assessment. The point of this example is that without NPYWC offering to pay for it, this person would not be able to get a full functional assessment and therefore is blocked from requesting NDIS Access.

Obtaining initial diagnoses in community in the absence of specialists is problematical. For instance, there are no specialists who can diagnose many conditions including autism, acquired brain injury and foetal alcohol syndrome. Visits to specialists involve travel to a regional centre or capital city, with accommodation and support for the applicant. This frequently does not happen - and sometimes, when it has been arranged, people do not attend, because of the time and effort involved in travel, or the necessity of responding to urgent culturally higher priority pressures in community.

Further issues relating to NDIS access include the strong cultural and social inhibition against giving personal details to people Anangu don't know and trust. Anangu perceive it is also culturally inappropriate to ask people questions, particularly relating to personal matters. Additional challenges arise from the fact that Anangu speak English as a third or fourth language. Interpreters are not available, and the use of local people is not always appropriate because of privacy concerns. Anangu not only do not understand the language used by assessors and planners but they do not understand the concepts underlying NDIS assessments, planning and operation. In addition, there are low levels of literacy in the NPY Lands. People do not value or trust paperwork, as the culture on the Lands is oral.

Assessment tools are not specifically appropriate for Anangu culture, society and environment. The person performing the assessment needs to be culturally aware and informed in order to make an effective assessment. This means having specific training and support led by Anangu, and spending time in the NPY communities. Assessors need an in-depth knowledge of the local situation and relationships if they are to take these environmental factors into account in their assessment.

Plan design

Many Anangu are not literate either in their own language or in English. Plans are developed and written down in English, in complex and often jargonistic language that is incomprehensible to Anangu, whose culture is oral, and first languages are Aboriginal languages.

Coordination of Supports funded hours

Many participants are funded for inadequate Coordination of Supports hours. Because Anangu live in a traditional culture, in extremely remote and poorly resourced communities, are often non-literate, speak only

limited English and do not understand the concepts involved in the NDIS processes, they require ongoing Coordination of Supports. Most would not engage with the scheme at all without this support. This is discussed further below, under plan implementation.

Goals

Because of high levels of poverty in the Lands, people are driven by basic needs for food, shelter and safety. Partly as a consequence of the necessity to satisfy those needs, and partly as a result of cultural tradition, Anangu live in the present moment, not focussing on consequences or planning for the long term.

Traditionally, Anangu live from day to day and do not plan for the future. A woman from a remote Northern Territory community expressed this: *Planning future is a risk, you know. If we plan the future now something will happen, like family passing away, and all that. That's get, hold us down. But really, in our culture and custom we don't really plan for the future. No, it's something new in our system, you know. We've got to learn about future.* This approach affects people's ability to plan for their future and establish and aim for goals of the sort required by the NDIS. Goals do not relate to people's way of thinking, do not reflect people's desire for access to basic needs, and often ask for services that are unavailable in remote communities

In its online video, 'What is the NDIS', the makers present one of the key ideas underlying the NDIS, that the goals in your NDIS plan **are specific to you, that Everyone has different goals...** Despite this, there is minimal allowance made by the NDIS for the different culture, lifestyle and circumstances of Anangu when compared to a notional 'mainstream' person with disability. For Anangu, some of the cultural and socio-economic elements of everyday life that affect people's relationship with the NDIS include:

- Having a mobile lifestyle- frequently moving between communities and sometimes regional centres
- Living in the present and not planning for the future, which affects both consideration of goals and participation in therapeutic programs.
- Living in extreme poverty, and so focussing on and competing for basic everyday resources such as food, a safe place to sleep and clothing
 - Prioritising everyday needs and family events over therapy
- Speaking one or several Aboriginal languages as their first language
 - Not understanding the language and the concepts expressed by the NDIS- in goals, plans, service agreements and 'explanatory literature'
- Living in an oral society rather than one which uses and relies on written documents
 - Anangu need to build a trusting, face-to-face relationship with planners in order to engage
 - Being unable to read or comprehend the documents they are asked to sign

The goals in people's plans are manufactured by planners, sometimes in conjunction with service providers. They are written in language that is not comprehensible to Anangu, and do not reflect what Anangu want, but what is considered to be 'best' for them. Often they refer to programs and services which are unavailable in the APY Lands, such as behaviour programs, skill development programs and employment funding. Sometimes goals are generic, and do not relate to the participant at all.

Examples include:

- A thirty-three-year-old man living with brain injury was given the goals:

I would like to develop critical life skills like learning how to cook, budget money and up-skilling, so that I can have a better quality of life and continue working in (the local) Media Centre. I will achieve this goal by working with my informal/formal/community supports to implement recommendations provided to me by allied health professionals and connect with service providers who will help me attend skill development programs and classes and provide me with support at work.

I would like to improve my functional capacity, so that I can become more independent with my day to day living. I will achieve this goal by working with my informal/formal/community supports to

implement recommendations provided to me by allied health professionals to improve my functional capacity.

I would like to improve my capacity to focus and pay attention, so that I can improve my reading and writing among other practical skills. I will achieve this goal by working with my informal/formal/community supports to implement recommendations provided to me by allied health professionals to improve my capacity to focus and pay attention.

- A girl (T) was one year old when her goals were developed, including this:

T would like T to be able to be able to feed independently without the feeding tube. T, for example, will begin to feed herself with her hand and a spoon. Supports: T, will be provided with opportunities at home and in Families as First Teachers to practice skills and strategies to support the goal. There will be a plan in place that assists T and Aunty T to achieve the goal.

All of this girl's goals suggest support from the Families as First Teachers program which is unavailable in the community in the NPY Lands where she lives

- A non-literate twenty-year-old young woman with vision impairment, hearing impairment, an intellectual disability and mental health issues was given the goal of starting a small business.

The young woman requires support and supervision to complete daily self-care and domestic tasks.

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 Anangu under their NDIS plan. Desires expressed by Anangu with disability for support 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 Anangu, they perceived that help needs to include the family of the person with disability. Because Anangu are unwilling to directly contradict others, they may not speak up about what they want. They need trusted advocates who are able to support them in speaking up, or are able to speak up on their behalf.

It is crucial that plans and goals are owned by the participants. The incomprehensibly complex language and concepts in which plans and goals (remembering that this is a concept that is not natural for Anangu) are expressed, is a major contributor to lack of ownership of the plans. The special 'codes' or phrases which are necessary according to the planners in order to access funds make these plans meaningless to Anangu and contradict the expressed aim quoted above that that the goals in your NDIS plan **are specific to you**. This minimises people's commitment to engage with the NDIS and with therapeutic programs

Geographical Isolation

There are limited services available for people with disability in the NPY Lands. Either service providers have to travel out to the Lands, where communities are between 250 and 1000 km from Alice Springs, or participants have to undertake the journey to Alice Springs or other regional centre in order to access services. The cost of travel can be extremely high. The limited bus and mail plane services to and from the Lands require passengers with disability to be able to board and alight *independently* and to be accompanied by a full-fare paying carer. This limits people's ability to travel as it represents a lot of money for someone on the Disability Support Pension. If a participant is unable to travel on the transport services to and from the Lands, and requires transport to Alice Springs, this must be undertaken in a four-wheel drive vehicle by a driver who has undergone appropriate training. If a powered-wheelchair-accessible vehicle is required, the costs are even higher, and, together with the provision of accommodation, can eat up a large portion of a participant's funding.

Service providers encounter similar barriers as a result of the geographical isolation and the limited infrastructure in the Lands. Accommodation is often unavailable in specific communities and road conditions vary depending on weather or may be closed because of cultural factors. The population of the NPY Lands is around 6000, spread over 350,000 sq kilometres. This raises the cost of accessing each participant by limiting

the number of people who can be visited in one trip. It also reduces the amount of time able to be spent in each community. There is no workspace in communities for visiting service providers to use. Schools, clinics and community offices are fully utilised, so working with participants happens in or outside their homes. This can mean that people are reluctant to engage fully as they perceive such public interviews as shameful.

Consequently, it is crucial that plans take account of the travel costs involved for both participants and service providers. The NDIS divides travel costs into hourly costs and non-labour costs. Currently many of these costs are unable to be charged, as participants have low numbers of hours, or we are unable to charge for non-labour costs. In particular, most plans for children have no core component, and therefore there is no possibility of charging non-labour costs, which are considerable in the remote situation, even when visit costs are divided amongst the people seen on each trip.

All service providers find this an issue. When one man's plan was reviewed recently, the allied health provider gave an estimate of 90 hours needed over the year. The NDIS funded 25 hours. Each trip takes 10 hours' travel, so this means he is funded for two trips during the year. Given his high level of need, this is poor service provision. A further concern is that if the participant is out of community for cultural or other reasons, and misses seeing the service provider, they will be waiting twice as long to see the provider.

Children's plans

Plans for children rarely include core funding, or funding for consumables. The NDIA considers that consumables should be an everyday expense. However, because people are living in extreme poverty, this results in consumables not being available for the child. The plans do not cater for travel costs, frequently having insufficient numbers of Coordination of Supports hours and/or no potential to charge non-labour costs.

The most effective way of working with children from the Lands is through a series of week-long 'intensive therapy' weeks. This removes the child and his family supports from the distractions which are constant in communities, and allows them to focus on working with the child's disability. It enables them to attend a series of short therapy sessions which can repeat and build on the child's and the family's learnings in a way which a two-monthly visit out bush is unable to do. Families are supported to attend the appointments. There have been significant gains with young children (seven and under) in this way, but the NDIA is reluctant to fund this process which involves transport, accommodation and support to attend appointments. This process has proven to be an effective and worthwhile early intervention. An example is the case of a three-year old child who is now starting to talk and walk, contrary to expectations.

Support for families

Many families with children who have a disability in the NPY Lands are in need of assistance in order to care for and work with their children. 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. In one family where two out of three small children are in need of intensive support, the family has asked repeatedly for workers to assist them. There is currently no funding for such help.

Other families who might benefit from access to therapists via telehealth do not have the capacity to utilise telehealth without assistance, lacking access to Wi-Fi and not having the confidence to deal with allied health professionals without support. They would have a vastly increased potential for benefitting their children if funding for support workers was available. These factors need to be considered in plan design.

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 Anangu families who took part in the Tjitji Atunymankupai Walytja Tjuṅangu (Looking after children with Disabilities from the NPY Lands) research were living off the NPY Lands, away from family, country and culture.

Planning meetings

Several cultural and socio-economic factors disadvantage Anangu and make these meetings meaningless. These factors include differing communication styles, literacy, language and conceptual understanding of ideas including forward planning and setting goals.

Culturally, Anangu need to know and trust workers and organisations before they are willing to engage with them. This process takes time and patience, and will not be achieved in the space of a single planning meeting. In addition, Anangu from the NPY Lands speak local Aboriginal languages, with English as a third or fourth language. They do not understand the language and concepts used in the NDIS, and interpreting is not a straightforward process for concepts which do not exist in Aboriginal languages. There are, in any case, very few qualified interpreters for Pitjantjatjara, Ngaanyatjarra or Yankunytjatjara, despite a high demand for them on the Lands, and the NDIS does not fund the use of local people as interpreters.

It is important for Anangu that meetings are held face to face, rather than over the phone or via other technological means, but this is happening less and less. They also need to have the chance to get to know people from the organization- when they meet a worker who is different from the person they have previously encountered, they need to start afresh getting to know and trust that person.

Anangu are also concerned to be heard- if they perceive that the person or organization they encounter is not listening to them or responding appropriately, relationships with that person or organization are not going to be positive. Ensuring positive relationships between Anangu participants and planners requires planners to spend time on the Lands with participants, listening and learning about culture and the socio-economic situation, and responding to their concerns.

The current planning process is inappropriate for Anangu from the remote NPY Lands in numerous other ways. Plans are written in English, in language that is incomprehensible to Anangu, whose culture is oral and based in traditional Aboriginal languages. There is excessive and complex paperwork for clients to sign, all of which means nothing to most Anangu. The goals in people's plans are manufactured by the NDIS planner, in conjunction with other providers present at the planning meeting (which may not be attended by the participant with or without an advocate and guide), rather than reflecting what people actually say or want. Many people do not understand what their goals mean. In Anangu culture it is considered extremely rude to contradict others, so that, even if they are present at the meeting, people are reluctant to speak up about what they want. This is one of the many situations dealing with the NDIS where Anangu need to be accompanied by advocates, people who have built trusting relationships with Anangu and who listen to their concerns respectfully and can help them speak up or can speak up for them when Anangu have concerns. Advocates also need to have an understanding of NDIS processes.

Implementation of plans

Lack of services

A minimal range of therapeutic services is available to people on the NPY Lands 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 such services available in the Lands, many Anangu with disability have NDIS plans providing funds for services such as social skills development and support, transport, behaviour support and early childhood intervention.

Providers are unable to travel with equipment, either for assessment or training, and so cannot provide a full assessment or therapeutic service. For people to access the equipment which will assist them in working with their disability, they would benefit from similar intensive period of therapy and access to therapeutic equipment in a regional centre as has happened for some children. This requires the appropriate funding in plans.

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 above, Anangu NDIS participants are unlikely to be aware of what is involved in the idea of these programs when agreeing to undertake them. One 60-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.

Because there are limited services available in the Lands, people are often 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. As mentioned above, the time and effort involved in travel, and the need to deal with other issues in community often leads to people missing specialist appointments.

The lack of providers servicing the NPY Lands creates a further issue, in that services such as those offered by allied health providers are overwhelmed, and this is often reflected in the difficulty of obtaining reports from them. In turn, this makes it difficult, if not impossible, to request changes to people's plans, argue for more appropriate reviews, and offer people effective support.

The lack of services creates a situation where there is no choice available for participants. A number of young men with disability on the NPY Lands refuse to engage with the NDIS because of shame around having a disability. They are unwilling to talk or work with female providers- both Coordinators of Supports and therapists as this is perceived as culturally 'wrong way'. Limited service provision is unable to cater for this element of traditional culture.

Coordination of supports.

The support coordinator's role is to facilitate a participant's plan. In remote communities this starts with building a trusting relationship with the participant as this is crucial for Anangu to engage with the plan. Working effectively with Anangu only happens when individual staff spend time in the communities long-term and build respectful and trusting relationships with clients. This is an important role for support coordinators- to act as the trusted point of contact for Anangu, who are faced with a situation which they don't understand. Support coordinators in this region need to be proactive in visiting clients, explaining plans, finding services, discussing them with participants, and introducing the therapists to Anangu. Plans are often under-utilised both because of the lack of services in the Lands and because participants do not understand and sometimes do not see the benefits of their plans.

In our experience with remote Aboriginal communities in Central Australia, the level of utilisation of a client's plan depends on effective coordination of supports as well as on the availability of services. As Anangu are not able to manage their own plans for the range of cultural and socio-economic reasons summarised above and are unlikely to develop this capacity, support coordination is crucial to the general utilisation of plans.

Because of the paucity of services available on the Lands where people live, the support coordination role has included sourcing and introducing therapists willing to travel to the Lands, and arranging for people to come into Alice Springs for clinic sessions. As part of the support coordinator role, we have arranged intensive clinic weeks when possible for specific children and their families as discussed above.

Support coordination hours are inadequate in many people's plans. NPYWC currently has a number of participants whose Coordination of Supports hours will all be consumed well prior to the end plan date, resulting in the necessity to submit a "Change of Circumstances" request, a lengthy and often unproductive process. When these plans are reviewed, Coordination of Supports hours are often funded at the same, or a decreased level, with no notice being taken of the fact that the participant's history documents a need for increased Coordination of Supports hours.

There are a number of issues with levels and modes of pricing for Coordination of Supports:

- There is no ability to charge for extensive high level administration time spent sorting out difficulties with billing
- Time spent in general preparation for trips out bush to visit participants (for such items as vehicle and emergency equipment maintenance) is not claimable
- Many participants have insufficient funding for travel and the associated non-labour costs to be claimed. For those that do have available funding, claiming travel can reduce their available direct service hours unacceptably.
- Currently NPYWC has six staff plus considerable management time absorbed by our NDIS participant work, and our income from billing the NDIA does not cover this. Our workers are subsidised by other, block-funded programs, a situation which is increasingly untenable. The NDIA is currently funding-a non-sustainable system. This largely relates to the extremely high overheads of working remotely, and is exacerbated by the high levels of administration and reporting required by the NDIA.

Assistive Technology

There are numerous challenges with the provision of assistive technology to Anangu with a disability because of the isolation of remote communities and the lack of available 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 involve sending it to a regional centre. This generally means months for the participant to be without their assistive equipment and involves high costs for the transport of, for instance, a power wheel chair to the place of repair.

There would 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 block funding or similar arrangements to be viable in remote communities

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 and mud, all within a short distance. People live outdoors much of the time, in this environment, and need sturdier equipment than might be the case in an urban environment. Alleviating these issues requires appropriate levels of funding in people’s NDIS plans.

Plan reviews

Plan reassessment meetings are very clunky. Phone and zoom meetings form by far the majority of these. They do not work for Anangu. In plan review meetings the NDIS planner will ask questions, use terminology, and speak in a way that is difficult for Anangu to understand, and they are left very confused. This can be exacerbated if planners speak English as a second language and are heavily accented.

Planners show no evidence that they are aware of, or need to take account of, such factors as the lack of supports available, the high cost of travel over long distances for providers, or the existence of cultural differences. Plan review meetings are not hosted as a discussion: the NDIS simply details the new plan funding. On occasion, some community connectors have included undeclared people such as potential service providers off camera in an online meeting. These people are then privy to the details under discussion. On other occasions review meetings of people for whom NPYWC is the Coordinator of Supports have been held without including NPYWC. The resultant plans have been drawn up without giving clients access to vital services, such as meals.

At plan review meetings it appears that the NDIS planners have not read Coordinator of Supports, Allied Health or SIL reports. It is rare to have a plan review meeting where the planner acknowledges having seen any of these reports. If the reports have been read by the NDIS planner, he or she is likely to quote pieces from the report that are aligned with, for instance, their agenda of money saving and the rest of the report is ignored. For example, reports relating to a client from the APY Lands with cognitive issues indicated that he

goes to the toilet anywhere he wants (including in public places) and is incapable of cleaning himself afterwards. Because he is not technically incontinent, the planner described this as 'no toileting issues'. He was denied SIL funding despite extensive occupational therapist reports indicating he is fully dependent on a carer for all of his activities of daily living and that his carer in community is ageing and herself an NDIS participant. No reason was offered for the denial of SIL funding, or suggestions as to further information that might be needed. When this plan was reviewed, the participant's Coordination of Supports hours were reduced, despite his hours having been expended for some time prior to the plan review.

The NDIS planners appear concerned about under-utilization of funds, but do not acknowledge when this is a result of the lack of services in the NPY region. A woman on the Ngaanyatjarra Lands recently had her funding for psychology cut due to her not engaging in a mental health care plan. This participant lives in the small community of Blackstone. No psychologist visits her community, let alone one that bulk bills. This participant is often without a phone, and has no access to emails so she can not engage with a psychologist through a Mental Health Care Plan via phone or telehealth.

At times, the NDIS has travelled to communities without informing the Coordinator of Supports, and met with participants and changed their plans, often reducing the funding. This is completely inappropriate because Anangu are unable to understand such discussions and their implications, and are reluctant to speak out to strangers whom they have no reason to trust.

Recently, in the course of a series of plan reassessments, which NPYWC as Coordinator of Supports was unaware of, a planner removed meals and linen services from a number of plans because "we don't fund meals and laundry very often at all". She argued that "It is very confusing for someone not working specifically in this region". If planners are not familiar with the region, they would benefit from involving the Coordinator of Supports in the reassessment, as suggested on the NDIS website.

Meals and linen services were reinstated in one woman's plan, but it was suggested that any problems with other plans should be addressed through submission of "Change of Circumstances" requests. The frequency with which NPYWC is told to fix any problems through such requests indicates a lack of any desire on the part of planners to **get the plan right in the first place**. It involves the Coordinator of Supports in hours of administration and paperwork in each case, and often there is no response or a flat, unexplained negative response from the NDIA.

Planners have stated that "Change of Circumstances reviews can be requested at any time so we don't need to and are not able to include predictive funding in plans". This means that the NDIA is only funding what already exists, rather than what people need. It means there is no capacity for the Coordinator of Supports or other provider to take advantage of opportunities to offer additional services or programs such as, for instance, community access programs. Over the years, NPYWC has worked productively with a number of providers (Men's program, allied health providers, local art centres etc.) to make a range of services available to NDIS participants on the Lands. Now, however, the money is not available in plans for these much-needed and beneficial services.

The NDIS operates on the understanding that people should be increasing their capacity over the duration of their plans, regardless of the limitations (e.g. extreme poverty, limited services, cultural factors) discussed in this submission. Funding is consequently expected to decrease over the years of the plan. However, life expectancy is very different for Aboriginal people living in remote communities, 65 for males and 69 for females, according to the ABS: <https://www.abs.gov.au/articles/aboriginal-and-torres-strait-islander-life-expectancy-lowest-remote-and-very-remote-areas>. It is unreasonable to expect people to be able to increase their capacity in this situation. However, plan funding continues to be reduced and assistance denied, for instance for a woman of 64 who lives with a congenital disability and has spent most of that time in a wheelchair in an institution where she could not communicate with the staff.

Community Access

Over the last couple of years, the NDIS has undertaken to block fund an organisation which works in three of the eleven main communities in the Anangu Pitjantjatjara Yankunytjatjara Lands (APY Lands) to provide community access for participants. In order to fund this, a set amount of either \$17,300 or \$19,500 was taken

from the 'back end' core budget (Social, Community and Civic Participation category) of a number of plans. That is, the amount was removed from the plans on the assumption that participants would benefit from the organisation's activities, with many participants then having a notional \$1.00 in their plans for Social Community and Civic Participation.

The process involved ending the participants' current plans and re-issuing them. The new plans were instituted without input from the participants or from the Coordinator of Supports who had been working with the participants for many years. A number of issues came up as a result of this process. By removing funds from people's plans, and giving that money to a specific provider, people were deprived of the opportunity to choose their community access provider, or to use these funds flexibly if they wished to do so. NPYWC was given a list of the participants, for whom we are Coordinator of Supports, whose plans were to be adjusted in this way. NPYWC responded, indicating which of these would be unable or unwilling to join in the proposed activities, but the advice was ignored.

As a result, many of the people from whose plans the money was taken were not people who would participate in these activities. Some habitually spent the majority of their time in town. Some were from communities where the organisation did not operate. When there is no staff in a specific community, funding is still taken from their plans despite no service being available. A participant with an acquired brain injury was not interested in the proposed social activities. Another person had strong informal supports, engaged in cultural activities without outside support, did not have concerns around community participation and did not wish to join in the proposed activities.

Participants who move to a community not serviced by the organisation, or go there for a period of time, are not refunded the money taken out of their plans but are unable to access the services.

Those participants who may wish to participate are frequently unaware of the program. NPYWC has requested information about the community access programs in order to inform participants so that they are able to take part, but no information has been made available.

The new plans are for two or three years and some of these participants have never been offered a plan review. Most plans were originally developed in 2019 or 2020, so now will not be fully reviewed for up to four years. The people re-issuing these plans have not met the participant or been to their home communities. They did not consult with support coordinators.

When the plans were re-issued, many of them had severely reduced funding levels, not just in Social Community and Civic Participation funding, but in all other areas of their plans. Discussion with the NDIS enabled the restoration of some, but not all, of these funding levels. One young woman had her plan reduced overall to 16% of its previous total, so that proposals for specialist therapies had to be abandoned. Discussion with the NDIA indicated that the plans should be accepted, and when funds run out, a "Change of Circumstance" form should be submitted- a process which is time consuming and results in lengthy delays before a response (not necessarily positive) is received.

Anangu with a disability living in town

Wherever possible, Anangu wish to live in community, on their ancestral Lands, surrounded by family. This was clearly indicated in the report of recent research, [A good life for Aboriginal people with disabilities from remote Central Australia- Walykumunu Nyinaratjaku; October 2018](#). Within the NPY remote communities, Anangu live with their extended families, often following a mobile lifestyle, moving between different communities and regional centres. People who have a disability move around as much as they are able, and want to participate in the events which take place in a range of communities, such as watching football and engaging in cultural activities including ceremony and funerals.

There are very few supports available for people with a disability living in the remote indigenous communities of central Australia. Allied health practitioners visit at best several times a year, and there are minimal disability support workers. Consequently, in order to access supports, people with a disability are sometimes forced to move to a regional centre away from the traditional lands, family and lifestyle which are vital for their wellbeing.

Accommodation provided in regional centres for Anangu who have left the Lands because of a need for services is rarely suitable. 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 away from the Lands 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.

If forced by circumstances such as the lack of disability support workers and other services in remote communities, to move to a regional centre such as Alice Springs or Kalgoorlie, Anangu are concerned to maintain their family and cultural contacts. They do not want to live by themselves, or with a group of strangers.

Case study

Two NDIS clients, life partners, are obliged to live in town because of their high level of need for support and the lack of services, particularly disability support workers, in their home community. Both want to live with each other. Both require a high level of daily living support. Whereas the husband previously provided his wife with significant assistance, (she is in a wheelchair and non-verbal), he now requires help himself since experiencing a severe stroke as well as becoming dependent on thrice weekly renal dialysis. He has not been funded for SIL, although his wife has. She was unwilling to take this up as it would mean separating from her husband. After extensive negotiations, NPYWC has been able to broker an agreement whereby he is able to live with her and contribute rent, while she has SIL.

While in SIL, they are unable to have their daughters or grandchildren visit. This makes it all the more important that they are able to visit their home community from time to time, as they have young children there, being raised by family members, and important family connections whose maintenance is crucial to their health and happiness.

Traditionally, Anangu live with extended family, and if they are unable to be in community, their primary concern is to have family come and stay with them from time to time. Wherever possible, people want to live with their partner or with their children.

It is important for Anangu with disabilities to be able to visit their home communities, particularly when there is a cultural obligation and emotional need to attend family gatherings at occasions such as funerals. The funding of supports to enable such 'reverse respite' visits is critical for people's social and emotional wellbeing. SIL options do not allow for cohabiting with or visits from family members and therefore many Anangu are reluctant to and sometimes refuse to take up such options. In other words, the lack of suitably flexible options often forces people to make decisions which pit their mental wellbeing against the best support options. The case study above illustrates this, and shows the inability of the NDIS to consider the bigger picture of a husband and wife who have varying but high levels of need.

The NDIA appears to be increasingly reluctant to fund SIL. However, within Alice Springs there are a number of local issues which affect the availability of accommodation, and make it impossible for Anangu to live under the ILO model or in mainstream accommodation generally.

- Applications for public housing have a waiting list of several years.
- Private rental costs are high (up to \$1200 weekly for a four-bedroom house), and the market is stretched, so that renters have to comply with stringent requirements and compete with people who are able, for instance, to produce a rental history and provide documented banking history, proof of identity and testimonials of good character. Anangu with disability are unable to provide these. In addition, as Anangu are dependent on the disability pension, very few options would be financially feasible.
- Aboriginal hostels are not an option for people requiring overnight care as they do not provide for accommodation for overnight workers.

As discussed above, Anangu live in the present moment, not considering consequences or planning for the long term. Anangu do not budget and their money management is further circumscribed by the need to share any resources they might have with a culturally specified number of family members. Any rental process would only be effective if it is mediated by a service provider and this mediation needs to be funded in people's plans.

For Anangu from the remote NPY Lands who move into town because of a lack of disability supports in remote communities, life is a compromise. There is no possibility of their living an 'ordinary' life outside their communities. They are away from the extended family, culture (including language) and country which is vital for their wellbeing. People are unable to live with their partners or their children when utilising SIL, and Independent Living Options present a range of difficulties discussed above. The importance of maintaining contact with their community-based culture and life is not recognised through support to return to community periodically or the ability to have family members stay or live with them.

In order to minimise the loss of the life they want to live, accommodation solutions for Anangu in town need to be flexible. Their plans need to be adequately funded to ensure Anangu with disability are living with people who share their language and culture, including living with close family members, catering for family visits, and allowing for appropriately supported return visits to community.

Information issues

Anangu prefer face-to-face negotiation and discussion of issues. Notification by mail and email is useless when few people are fully literate in English. As indicated above, this applies to the provision of initial information as well as to notification of whether people have been accepted into the scheme, and what acceptance means in terms of eligible supports. People need to hear about the options open to them and have time to absorb and consider the information. They need to have the opportunity to ask questions in a non-threatening environment. On receipt of their plan by letter, it is common, for instance, people to see a large money amount and think the money is available to them to purchase a car or other item.

Anangu do not distinguish between some disabilities and chronic, acute or palliative health conditions, considering instead the effect on the lives of the people concerned. They find these distinctions unrealistic and confusing. Where this is a factor in accepting or rejecting a person from the scheme, the difference needs to be straightforward, and be expressed in clear language.

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 for repeated explanations of the way the NDIS works. As discussed above, the complexity of the NDIA systems means that local people employed as interpreters and cultural brokers (the community connectors) 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.

Lack of understanding of the NDIS is also a problem with service providers on the Lands, who can spread misinformation, and who place all sorts of requests and expectations on the Coordinator of Supports, requiring significant time from the Coordinator of Supports to explain their role and that of the NDIS to providers as well as participants. Recently a mental health worker reached out to a Coordinator of Supports living and working on the Lands, requesting that a woman with no diagnosed disability, no NDIS plan, and no behavioural issues be moved into supported accommodation funded by the NDIS. Service providers regularly email the Coordinator of Supports asking for such things as emergency respite, or the removal of specific people from the lands due to difficult behaviours or domestic violence. There is a lack of understanding that the NDIA does not provide emergency supports.

Similarly, an organisation which manages the remote community connectors in one State expected that NPYWC, as Coordinator of Supports, should be able to keep a particularly vulnerable woman, with low cognitive ability, safe from abusive partners and indicated they would advise the participant to change Coordinator of Supports if this was not achieved. The organisation concerned suggested sending the woman to Adelaide for respite from violence and sexual exploitation, but had not considered the issues involved, including whether Adelaide would be a safe place for her.

Another barrier is the inability of many Anangu 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 Anangu 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 Anangu wanting assistance and not understanding why they are directed back to their chosen Coordinator of Supports. Anangu 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 confusing. 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 NDIA asks for a number of reports from the Coordinator of Supports and has exponentially increased the amount of information required in recent years. Implementation reports now start out at 7 pages, and progress reports at 9 pages. Filled in, they are much longer. Much of the information required is not relevant or meaningful for Anangu. The input requested is repetitive. Comment requested on progress the participant perceives with achieving their goals is one example. As Anangu often do not understand or relate to their plan ‘goals’, this is meaningless. Filling in these forms takes many hours of a participant’s plan, when the participant may already be short of Coordination of Supports hours. Sometimes the participant has no remaining Coordination of Supports hours when the report is due to be submitted. Despite the effort which goes into preparing the reports, at re-assessment meetings there is no indication that the planner has read the report or taken note of the content. This reduces the hours of direct support available to the participant, for no gain.

Concerns about the language and concept of goals in plans are discussed above.

Availability, responsiveness, consistency, effectiveness

Inability to listen

It has become extremely difficult to have any meaningful communication with the NDIA, either for participants or for NPYWC as Coordination of Supports providers. The Coordinator of Supports needs to be able to work closely with a single key person who is directly contactable within the NDIA. This needs to be a person who is locally based and who has or can built up an understanding of local circumstances and appropriate approaches. This would enhance the Coordinator of Supports' ability to work efficiently, be more responsive and maximise the benefits to participants. Staff changes and divers contact points do not assist this process. Neither does being referred to a general (1800) phone number, which frequently leads to multiple contacts with people unacquainted with the specific needs of the cohort we work with, frustration and conflicting information being given. Similarly, for queries relating to many participants, NPYWC is required to email "enquiries". Responses to these emails take a long time, and are often not helpful.

Participants are also unable to access the NDIA. We recently supported a participant in a wheelchair to try and speak with the NDIA about her plan. After queuing, the participant spoke to an administration person to explain the issue. He then disappeared, and later, a person came out with the response that "someone will be in touch". This woman's brain injury affects her speech, and she is non-literate. In other regions, people have direct contact with their planner if they have a query.

The NDIS has demonstrated an inability to listen to advice around the desires of participants, their needs, and the limitations arising from their situation and their circumstances. For instance, a complaint was submitted recently on behalf of a client who has mobility issues, and a decision was made to offer her an electric scooter so that she could move around the community. However, NPYWC was informed that a letter had been sent to the participant in the community, despite the community having no mail service- letters from the mail bag are placed on a table in the community office on the off-chance that addressees will happen to flick through them and find any addressed to themselves. We have repeatedly pointed out to the NDIA that Anangu are not able to read and many have minimal English, and asked for communications to be directed through the Coordinator of Supports.

The NDIS does not listen or respond appropriately to information submitted to them. For instance, they were informed about a client whose cognitive disability puts workers at risk, and that he should always have two workers present. He was, however, funded for services with a ratio of 1: 3 and 1: 4, and therefore cannot utilise those services. In another instance, a child born with a congenital disability (left side paralysis in utero) is described as having a 'developmental delay' in spite of having a clear diagnosis and the need for several intensive therapeutic disciplines.

There is no indication, when new plans are issued or responses are received to "Change of Circumstances" requests, that the NDIA has considered any of the information submitted in the reports and forms required by the NDIA. There is no detailed response to points raised in the request. This is also discussed above, under plan reviews.

Some of the NPYWC clients we work with have now become PACE participants, and it has proved extremely difficult, if not impossible to communicate with the NDIA over issues arising for these participants. Out of 5 plans on PACE, two are set up correctly. One of those two clients has passed away. When another plan is clicked on, a Salesforce error message appears. There is no full access to another plan, and a further one has plan dates of 'nul to nul' but also has a plan on the old portal. In addition, one client has disappeared from the old portal but isn't on PACE. And a two year old has had a plan since August that cannot be billed to. It's been sent to the old portal, to the new portal, to the old portal and still NPYWC can't do a service booking for it.

When these issues have been followed up by phone, the NDIA say they will fix the problem, but this has not happened yet. Emailing the same concerns can take two or more months for an unhelpful reply, such as 'you didn't provide the NDIS number,' when the number actually was provided in the original email. Further correspondence has not been acknowledged or replied to.

Recently a staff member received an email from the NDIS saying they couldn't reach her by phone and the question she had raised was too complex for them to respond via email, so she needed to ring them. There

were no missed calls on either of her phones. When she rang them, it concerned a problem she had had in October of the previous year and that had been resolved in November.

In another instance, the twenty-year-old young woman with vision impairment, hearing impairment, an intellectual disability and mental health issues referred to above, received an extensive assessment by allied health therapists who recommended she attend a series of week-long sessions in Alice Springs. If she were to continue to receive 4-8 hours per year of service delivery, as she had been doing, her condition would continue to deteriorate. The recommendations were supported by research and a knowledge of this young woman and her circumstances. Despite this report, the young woman was offered a low-funded two-year plan with no capacity for therapeutic sessions in Alice Springs, and limited funding for access to therapeutic visits in community when the cost of provider travel is taken into account. The new plan only looks at her vision loss and does not factor in her intellectual disability, psychosocial diagnosis or her hearing loss. It does not look at her circumstance as a whole or take in her family's limited capacity to offer her appropriate support while dealing with their own health issues. She is isolated from her peers and has identified that she finds it hard to make friends. Family has concerns around how she processes anger and there is concern about substance misuse.

Recently the NDIA refused to acknowledge a participant's need for an upgraded wheelchair until the information about her situation had been repeated in a doctor's letter. The information was indicated on her hospital discharge summary and in reports from occupational therapists, but because her primary disability was given as cognitive, the NDIA refused to consider some of her needs until a doctor's report was organised. The participant's severely limited mobility arises directly from her congenital brain abnormality. NPYWC is still struggling to obtain a hoist for this woman. She is not the only person in this situation.

Variations in plan funding

There are a number of concerns around plan funding. Funding detail varies from planner to planner. The plans developed for our clients sometimes appear to have funding allocated arbitrarily. To take one of the simplest examples, a person who has used all of their Coordination of Supports hours early in the plan will be given the same or a smaller number of hours as in their previous plan when the plan is renewed, despite what is written in the end of plan report. On the other hand, a person who has accessed minimal services may be funded more generously.

The planning process needs to be considered in the context of responding to the needs and personal goals of each individual person with a disability. Because plans are made for individuals from widely differing cultures and backgrounds with access to a widely differing range of services, plans need to reflect the specific situation for that person. In practice, planning appears to operate within guidelines which do not reflect the culture and situation of Anangu and rarely take account of the needs of individual participants. One example of this would be the instance of a woman in a wheelchair who is non-verbal, but who was funded at a level which meant she could receive only physiotherapy and occupational therapy, but could not afford to access speech therapy to work on her communication skills.

Choice and control including availability, accessibility, cost and durability of those services;

Anangu who are NDIS participants do not perceive they have any choice and control. This is a result of a number of factors, including:

- A lack of understanding of the NDIS concepts and processes by Anangu. People who are unhappy with their plan or providers are unable to argue for a change of provider, despite often feeling a general distrust of government support.
- Lack of available services in the Lands. Often there is only one option for service provision and visits to the Lands are irregular, every couple of months at best.
- Lack of services and funding for services offering practical everyday help, which is what is wanted by Anangu
- The costs of service provision in remote communities, which mean that services only travel to the Lands if they have a number of participants who can share costs. This model of shared contributions

means that people are allocated to a provider according to their community. NPYWC is currently working with additional providers to travel to the Lands, who assess that each session is likely to cost \$1500, despite working with all of the participants in a specific region.

- High turnover of service provider staff leading to a lack of engagement on the part of Anangu. Young men, particularly, find that working with female providers is wrong. Anangu culture requires that people engage with those of a similar gender.
- The model of community access funding discussed above is a prime example of people being without choice and control. The NDIA was informed early in the operation of this program, that a number of our clients **did not want** to be involved, but this was ignored by the NDIA and the funds continue to be removed from their plans.
- The way plans are written (language, goals etc.) does not align with Anangu culture or lifestyle. One participant stated that he felt the NDIA wanted him to learn to live '**white fella way**'

Disability Support Workers

Some 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 Anangu with disability. However, there are no disability support workers in most communities in the NPY Lands.

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 (under the age of 50) who have a disability.

Any other related matters

Vulnerability of Anangu - shonky providers

Because Anangu do not have a good understanding of the way the NDIS operates and the implications of signing forms, they are especially vulnerable to dodgy providers. Our clients have encountered these people both in community and in town. For instance, a couple of taxi drivers were signing people (whom they perceived to have a disability) up when they took a taxi ride in Alice Springs. The drivers then billed for non-existent services. Another woman was bribing people with food to sign up with her, and then removing funds from people's plans similarly. As NPYWC becomes aware of these operators, we notify both the NDIA and the Commission, but it then creates difficulties in having funds available for legitimate providers.

The NDIS Aboriginal and Torres Strait Islander Engagement Strategy

The NDIS Aboriginal and Torres Strait Islander Engagement Strategy, dated 2017, shows an awareness of some of the issues raised in this submission. It states:

"Meaningful engagement with Aboriginal and Torres Strait Islander peoples with disability – the views of Aboriginal and Torres Strait Islander peoples with disability are central to the design, delivery and evaluation of policies and services which affect them. There must be respect for the cultural knowledge that exists in Aboriginal and Torres Strait Islander peoples with lived experience of disability. The involvement of Elders and representative organisations is necessary for strengthening trust in government efforts"

It undertakes that staff will

“Practise the skill of sitting down and listening” and “Avoid bureaucratic language and direct forms of questioning,”

And makes a commitment that

“All National Disability Insurance Agency staff will be trained to understand and engage with Aboriginal and Torres Strait Islander people and communities in a way that demonstrates respect and support for Aboriginal language, heritage and culture ...NDIA staff will listen, learn, build and deliver.”

As this submission shows, the engagement policy has not been translated into practice, and the actions of the NDIA and its staff on the ground are often contrary to, and are moving further away from the NDIA’s stated aims and commitment.

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