

# Tjitji Atunymankupai Walytja Tjuṅangu



Looking after Children with Disabilities  
from the NPY Lands





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Cover design by Margaret Smith, from Imanpa community. The artwork depicts families looking after children with disabilities. Some children are travelling by bus to disability accommodation away from the Lands (centre of painting). The wavy lines indicate the worry surrounding families caring for the children with disabilities. Margaret also designed the logo.



This report includes children's artwork from the NPY community schools.

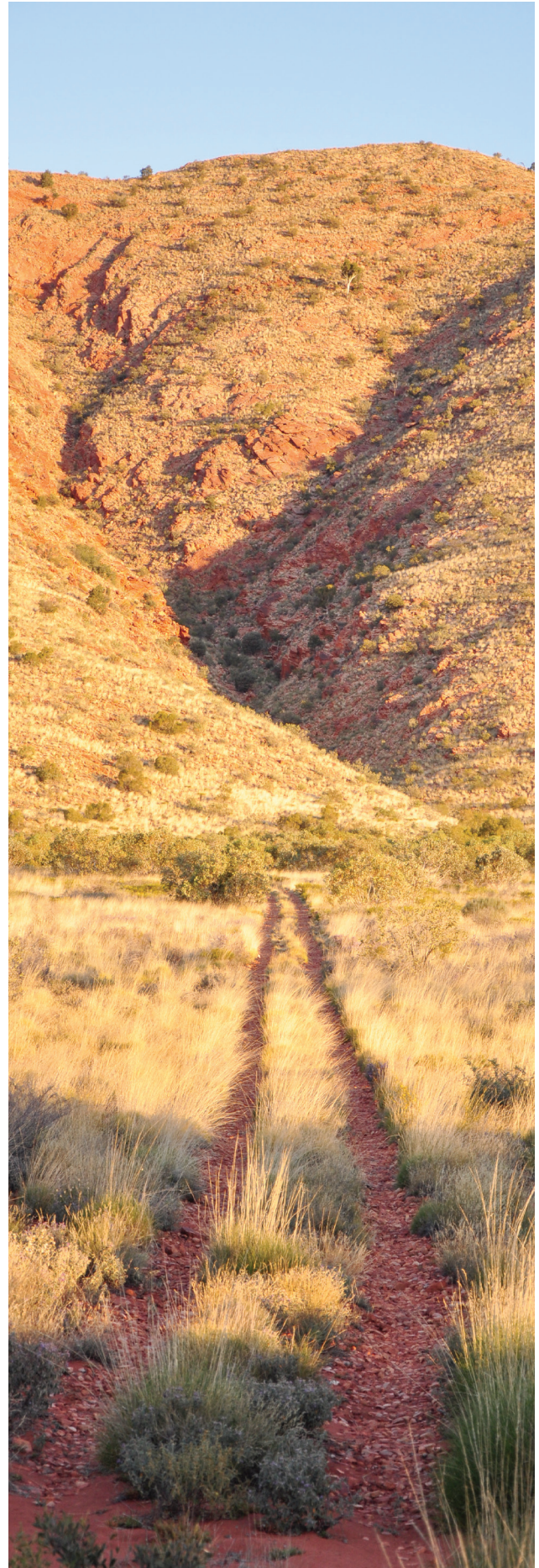
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## 1 EXECUTIVE SUMMARY

This is the final project report for the Tjitji Aṭunymankupai Walytja Tjuṭangku collaborative project initiated by the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation (NPYWC). The title of the project in the Pitjantjatjara language means 'Families Looking After Children'. This report discusses what makes a good life for Aboriginal children with disabilities and their families from the Ngaanyatjarra, Pitjantjatjara Yankunytjatjara (NPY) Lands in Central Australia.

Aṅangu are the traditional owners, the Aboriginal people, of the NPY Lands. Families looking after children, 0 to 18 years of age, with disabilities were asked to share their experiences as carers and to suggest improvements for their lives and those of their children with disabilities. Researchers also spoke with workers from organisations that support children from the NPY Lands about the assistance they perceived was needed for those families and children to live the life they choose.

Aṅangu is the Pitjantjatjara and Yankunytjatjara word for 'people'. The word Aṅangu is used in this report to represent people from all of the language groups from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Lands. In particular, it is used to distinguish Aboriginal people of the Lands from non-Aboriginal people. Aṅangu move freely across the Lands and understand all the local languages. The research was conducted across the NPY Lands and there was no differentiation in data collection or analysis between people from the Ngaanyatjarra, Pitjantjatjara or Yankunytjatjara Lands.

This document reports on the findings of the study and suggests culturally responsive support mechanisms to enable families of children with disabilities on the Lands to live a good life. Detailed recommendations are given in Chapter 6 of the report.

### 1.1 Summary of Findings and Recommendations

#### 1.1.1 Families Looking After Children with Disabilities on the NPY Lands

A number of issues worried both the families of children with disabilities who were living on the Lands and workers from organisations that supported them.

##### 1.1.1.1 Assistance with Basic Needs

People living on the Lands and caring for children with disabilities asked for practical help - food, bedding, clothing and household goods. The report therefore recommends assistance with their basic needs. People who are worrying about where their next meal will come from or where they will sleep each night are unable to consider more complex issues related to the needs of a family member with a disability.

##### 1.1.1.2 Day-to-Day Care Support - Workforce Funding, Development of a Local Workforce, Advocacy

Both families and workers pointed out the lack of day-to-day support for the care of children with disabilities who live on the Lands. The lack of support services was reported as a major reason for sending children with disabilities, particularly those with high-care needs, away from their families, the Lands and their culture. It is crucial that culturally appropriate in-home care support be available on the Lands to assist families of children with disabilities.

The report recommends a two-pronged approach to making day-to-day care support available on the Lands. Disability support workers need to be funded immediately to live and work in remote Aboriginal communities. Over the longer term, an Aṅangu workforce needs to be developed to take up this role. Aṅangu taking up disability support positions will need assistance and training to move into the workforce as well as ongoing support and supervision.



Another recommendation, described in section 1.1.2.1, is that advocacy and case management services be available on the Lands to help Anangu families who have children with disabilities negotiate the complex issues facing them.

#### **1.1.1.3 Funding for Specialist and Therapeutic Services**

Some Anangu asked for additional specialist and therapeutic services, and many workers noted the lack of these services and the need to make them available regularly and in a culturally appropriate way. Specialist and therapeutic supports are necessary to maximise the development of children with disabilities and to allow them to participate as fully as possible in community life. There were limited Early Childhood Early Intervention (ECEI) services. Many children did not have a diagnosis for their disability, a situation exacerbated by the lack of culturally appropriate assessment tools. Diagnosis not only assists treatment, but also enables the funding of assistance, such as teachers' aides.

Increasing the presence of specialist and therapeutic services on the Lands will require specific funding, possibly targeted block funding, because the geographically widespread communities and low population numbers on the Lands make it difficult for organisations to survive economically. All services need to operate in a way that aligns with Anangu cultural expectations, as discussed in section 1.1.1.6.

#### **1.1.1.4 Increased Resources for Schools**

Most people considered that schools were providing good help for their children, but many families were concerned about children being teased by their peers. Sometimes this meant that children were reluctant to or did not attend school. Several Anangu requested additional help for children with disabilities in school, and a number of workers pointed out the need for in-school resources to enable one-to-one or in-class assistance for children with special needs. These recommendations are included in the report.

#### **1.1.1.5 Funding for Respite Breaks for Families**

Families are the carers for children with disabilities, and many people stressed the importance of having a break from the pressures of providing care - by having a respite break in a regional centre. The availability of day respite on the Lands is also limited. Funding needs to be available for respite breaks on and of the Lands in order to enable families to continue providing care for their children with disabilities.

#### **1.1.1.6 Cultural Appropriateness - Cultural Orientation, Relationship Building, Working Within Culture**

A further concern was the culturally inappropriate way that many organisations were working with Anangu. Anangu interact with people they trust and they are much more likely to engage with services when they know and relate to the workers. This is not possible when workers visit a community for a few hours or a day once every few months, or when there is a high turnover of staff. These situations occur frequently in remote communities and affect people's willingness to access services. Language difficulties and cultural misunderstandings are additional factors that service provision organisations need to take into account. The development of a local disability support workforce would be likely to alleviate some of these issues. Such a workforce would need to operate on a flexible working model in order to accommodate cultural requirements and would require ongoing support and supervision. Cultural orientation, guided by Anangu, is crucial to enable organisations to work effectively in the Lands, and to encourage Anangu to engage with those services. Organisations need to recognise and work with cultural differences from mainstream society, including the traditional understanding of family responsibilities for children, and parenting roles.





#### **1.1.1.7 Supported Accommodation for Children with Disabilities on the Lands**

There was also a suggestion that a supported accommodation service for children with disabilities be established in the Lands. Such a service would provide accommodation for children with high-care needs, be a centre for children off the Lands to visit their home and culture, and support families on the Lands by caring for children while families have a respite break.

#### **1.1.2 Children with Disabilities Living off the NPY Lands**

Many children with disabilities had left the Lands because of their care needs. Several had a period of regular off-the-Lands respite before moving away from their families, homes and culture. These children moved into foster care or institutional care and often their families lost contact with them.

##### **1.1.2.1 Need for Day-to-Day Care and Advocacy Support**

The main reason for children being sent away from the Lands was the lack of support available to families looking after children with high-care needs. This outcome could be minimised with the development of a disability support workforce, in conjunction with advocacy and case management support on the Lands for families of children with disabilities. Such support should include information around the nature of disability, therapy and care assistance, as well as improved therapeutic services in communities. The support would require block funding in order to maintain a presence on the Lands

##### **1.1.2.2 Maintaining Contact with Children - Parental Rights, Support for Visits**

Anangu whose children with disabilities had left the NPY Lands wanted support for visits with their children. The report recommends that families retain their parental rights and rights of contact with those children, and that financial and logistical assistance be made available for family visits, either off, or where possible on, the Lands.

##### **1.1.2.3 Assistance for Families Supporting Children with Disabilities off the Lands**

Families who were living away from the Lands because of the high-care needs of their children with disabilities also needed support. They required help to negotiate accommodation and transport systems in the regional centres where they were living, and assistance to enable them to return to the Lands from time to time for the sake of their own cultural and emotional wellbeing.





## 2 TJITJI ATUNYMANKUPAI WALYTJA TJUṅANGKU RESEARCH PROJECT

### 2.1 Background: Families of The Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Lands

The NPY Lands (the Lands) comprise 25 very remote communities and homelands across 350,000 square kilometres of the central Australian desert. The region includes the Shire of Ngaanyatjarraku in Western Australia, the four southernmost communities of the Northern Territory and the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands in the northern part of South Australia (Figure 1). Access to almost all of these communities is by unsealed dirt roads that are subject to closures for cultural activities and wet weather, or via the mail planes.



Map of the Ngaanyatjarra, Pitjantjatjara Yankunytjatjara lands, Central Australia.

Anangu are the Aboriginal people of the NPY Lands. The Aboriginal population of the region was approximately 5,300 in 2011<sup>1</sup>. Their first language is one or more of the local languages - Ngaanyatjarra, Ngaatjatjarra, Pitjantjatjara or Yankunytjatjara. The arrival of European people in Central Australia is relatively recent and the subsequent establishment of remote communities is within living memory for many of the older people.

Children aged 0-14 represent around one-third of the national Aboriginal population compared to 18% of the non-Aboriginal population<sup>2</sup>. In the NPY Lands, in 2011<sup>1</sup>, 38% of all Aboriginal people were aged under 20. According to the Australian Bureau of Statistics (ABS), Aboriginal children aged 0-14 years are more than twice as likely as non-Aboriginal children to have a disability (15.2% compared with 6.6%)<sup>3</sup>. Under the ABS definition of disability, a person has a disability if they report a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.



## 2.2 Project Aims

There is limited research from very remote communities on the views of Aboriginal families whose children live with a disability. This project, instigated by the NPYWC, aimed to identify the supports and mechanisms required for families (the main care providers) of children with disabilities from the very remote NPY communities in order for them to live the lives they desire. A further project aim was to identify, from the perspective of Aboriginal families and service providers, the factors that influence families of children with disabilities to stay in or leave their communities. It was anticipated that the research findings would suggest culturally responsive supports for families of children with disabilities on the NPY Lands. In this report, the term 'children' is used to include children and young people aged from 0 to 18 years.

The project, undertaken at a time when the National Disability Insurance Scheme (NDIS) was rolling out across Australia, explored the challenges for Anangu living in very remote communities who have children with disabilities. A related project, Walykumunu Nyinaratjaku<sup>4</sup>, considered what makes a good life for Aboriginal adults with disabilities from the NPY Lands. The report is available online. <https://www.npywc.org.au/wp-content/uploads/sites/45/Walykumunu-Nyinaratjaku-October-2018.pdf>

Both projects are collaborations of the NPYWC; the Faculty of Health Sciences, University of Sydney; the Poche Centre for Indigenous Health and Well-being, Northern Territory; and the Centre for Remote Health, a joint centre of Flinders University and Charles Darwin University. The project reported here was funded by an Australian Research Council Discovery Indigenous grant and conducted between 2016 and 2018. The directors of NPYWC oversaw the project, providing governance and guidance. State and Territory ethics committees gave approval to conduct the interviews that were held between July 2016 and September 2017 with two groups of people:

1. Anangu families of children with disabilities from the NPY Lands.
2. Workers providing supports to Anangu children with disabilities from the NPY Lands.

The project focussed on the views of the families rather than of the children themselves. The one exception to this was a young woman who was interviewed along with her family members. As work in related projects (Walykumunu Nyinaratjaku<sup>4</sup>, They Might have to Drag Me Like a Bullock<sup>5</sup>) indicates, family and carer views are not always aligned with the feelings and desires of the person being cared for. This project represents what families identified as important for themselves and their children with disabilities in order to live the life they desire.

## 2.3 Participants

69 PEOPLE WERE INTERVIEWED
41 Anangu from the NPY Lands who were family members of children with disabilities
One young person with a disability
27 workers from 9 organisations providing supports to families who care for children with disabilities from the NPY Lands

### 2.3.1 Anangu

The project sought information from families of children with disabilities from the NPY Lands. The NPWC Directors chose the interviewer, and where appropriate, she worked with a *malpa* (an Anangu



co-worker). Interviews, which were audio-recorded with participant permission, were conducted in the local language, English, or a mixture of the two, according to the preference of the person being interviewed. Interviews in Aboriginal languages were translated into English during transcription. The interviewer spoke to 42 Anangu in 11 different communities across the NPY region. Thirty-nine participants were female. Only one child with a disability, supported by family, was interviewed. Family members interviewed ranged from 22 to 75 years old, with an average age of 48 years, and comprised siblings, parents, aunts and grandparents of children with disabilities. The report refers to family roles as described by the participants. These may sometimes differ from non- Aboriginal descriptions of family roles.

The 33 children with disabilities who were discussed by Anangu were aged from five to 16 years old, with an average age of 10 years. There were almost twice as many boys as girls. Twenty-three of the children were living on the Lands and ten were living in regional centres or cities. Three of those living away from the Lands were living with family who had moved away from the Lands in order to support their child. Table 1 provides a breakdown of the disability types of the children who were discussed in interviews with Anangu families.

**Table 1: Primary Disability Types of Children whose Families were Interviewed<sup>1</sup>**

Primary Disability Type	Number of Children
Cerebral palsy	4
Global developmental delay, often with associated epilepsy, hearing or speech issues	4
Hearing/speech impairment	4
Intellectual disability (including Down syndrome)	2
Attention deficit hyperactivity disorder (ADHD)	3
Psychological issues	3
Complications after polio/meningitis	2
Other	11
<b>Total</b>	<b>33</b>

### 2.3.2 Workers from Service Provider Organisations

Twenty-seven workers were interviewed from nine organisations providing supports to children with disabilities from the NPY Lands. The organisations offered services including disability support, primary health care, allied health care, respite and specialist schooling. Two were Aboriginal community-controlled corporations. The workers who were interviewed spoke about a number of children with disabilities with whom they came into contact. Some of these children were additional to those discussed in the interviews with Anangu.

The research team requested ethical approval to access schools on the NPY Lands. The ethics committees in South Australia and Western Australia declined the requests due to staff shortages in the education sector. Approval was received to access the education sector in the Northern Territory.

1. Many children do not have an official diagnosis for their disability.



## 2.4 Data Analysis

Interviews were qualitatively analysed by research team members using coding, constant comparison and thematic analysis techniques. Following the initial analysis, a malpa working group verified the de-identified research results and clarified cultural understanding. The malpa group assisted with the interpretation of the findings and the contextualisation of words and phrases used by participants. The group also helped to develop culturally appropriate research dissemination strategies. The findings of the research are discussed in Chapters 3 and 4 of this report: “Findings: Looking After Children with Disabilities on the NPY Lands” and “Findings: Children with Disabilities Living off the NPY Lands”.



## 3 FINDINGS: LOOKING AFTER CHILDREN WITH DISABILITIES ON THE NPY LANDS

### 3.1 Life in Remote Communities

#### 3.1.1 The Setting

Children with disabilities who live on the NPY Lands are cared for by their families. In the NPY Lands, the term, 'family' includes extended family, whose members may live in one or more houses across several communities. Anangu who speak English do so as a second, third or fourth language. Remote communities usually (but not always) have a school, an administrative office, a store, a clinic, a family centre and an art centre. Some have preschools and play groups. There are limited facilities, support services and therapeutic services available for families looking after children with disabilities. Some services are based in one community and visit other communities, but the majority of those disability services and specialists that do visit the Lands fly or drive in from a regional centre or capital city, which may be 1,000 or 1,500 kilometres away.

#### 3.1.2 A Good Life: What the Children Enjoy: 'running round with kids'

This section describes family members' observations of the activities children with disabilities from the NPY Lands enjoy. Families said that the main things their children with disabilities liked doing were playing and socialising with their friends and joining in family activities. One woman described this as 'playing football, running round with kids, playing with kids.'

For some children with disabilities, taking part in these activities was difficult, as described by this mother when asked what her daughter would like to do, but was unable to. She responded: 'To play with other kids', but was concerned about 'other kids teasing, talking, like "big head" ... Maybe push her and hit her head ... dangerous'.

Many families reported that children with disabilities liked playing sport - particularly football, but also swimming and baseball. Children also enjoyed hunting and camping, particularly with their families, as this father explained:

*He likes to go out hunting and goes places with me and he likes to play footy. He likes to kick a goal and play a game.*

Singing, music and dancing were also favourite pursuits, as these family members recounted:

*She's always singing songs ... She always likes singing. She likes music.*

*Yes, when they listen to, you know, tapes? (Or music on a) USB. Listen to the music, and he sings, that boy, and he play around with the drums.*

One woman summed up a good life for her niece:

*A good life would be to go out for picnics. And to go swimming to waterholes, and, like, to babysit little babies and help with small children, and to go to school.*



CHILDREN WITH DISABILITIES ENJOY:

playing with friends,  
playing sport,  
playing, listening to and dancing to music,  
and joining in with family activities.

### 3.2 Worries of Families Caring for Children with Disabilities on the Lands

Family members were concerned about both the wellbeing of their child with a disability and their role in looking after that child.

#### 3.2.1 Keeping Children Safe and Well on the Lands

Families were worried about protecting the children from further harm or injury associated with their disabilities. A woman spoke about her grandson, whose brain tumour caused frequent fits:

*And we always, we were really close, and looking after him, taking him out for ride and all, in the bush. Yes, we families were really close to him. But when he climb up the tree, we always tell him, no climbing on anything, trees, or anything. We always make sure he is on the ground, walking around.*

People were concerned about the suffering experienced by children with disabilities, as this woman was for her daughter:

*She calls out to me, 'Mum! My head is beginning to go all funny.' I go to her and I hold her in my arms while her head moves around. I hold her close.*

At the same time, families were aware that children with disabilities were vulnerable, and they expressed their worries about the children starting to sniff petrol, try gunja (marijuana) or smoke tobacco. The mother of a ten-year-old boy with a disability told him off for sniffing petrol:

*He said to me that he would give it up and not sniff. I told him, 'If you sniff petrol, you'll get an acquired brain injury and be brain damaged all your life'.*

#### 3.2.2 Shame

Anangu reported being affected by shame in a number of ways. As well as the shame and embarrassment experienced by children being teased by their peers, a senior woman explained that many people are ashamed of children with disabilities and want to *'keep it hidden away. They don't want everyone to know about it'*. She added that people will repudiate any suggestion (from other Anangu) that a child might need special help, often responding that the other person should look after their own children and stop worrying about someone else's. Consequently, many families will not seek help for their children, as that would involve admitting publicly that there is something wrong and this might reflect negatively on the family. This feeling of shame relates to having a child who is 'different', as well as emphasising that difference by having to ask for help for the child. There may also be an element of concern or guilt that the parents are in some way responsible for the disability and that they might receive blame and/or payback.

Most families were concerned about the level of teasing and bullying that children with disabilities experienced from their peers. One young boy's aunt explained:





*...a lot of kids were teasing him... and so he just stopped going to school... when he was, like, six years old, 7... Sometime we take him to the school ... sometime ... he just ignores us and tells us, 'No, those kids are always picking on me. I want to stay at home'.*

Families reported that children were ashamed or embarrassed about their disabilities, which affected their enjoyment of school and socialising with their peers. One mother said, *'Sometimes they do tease her, and that makes her shy and embarrassed'.*

Feelings of shame also affected family members who were caring for children, as several workers supporting people on the Lands discovered:

*Once again, mum tried really hard, but the boy was non-verbal. It got to the stage where he was... being inappropriate and they didn't know how to handle that. There was a lot of shame.*

*...the family didn't agree with keeping the kid back... in kindergarten. They wanted him to go to school... It was the first time that it had come home to them that their kid was gonna be a bit slower and that he might stand out a bit, and they didn't like that their kid was standing out from the crowd.*

Families were upset and felt ashamed because some children had difficulties with managing their emotions and behaviours; for instance, getting angry and responding violently to other people. This was seen as inappropriate behaviour, as one grandmother described:

*He was born with mental health and behavioural issues... He has serious problems. I did speak to the doctor about him, because he was not easy to look after. He would get really angry very quickly and lash out.*

FAMILIES' WORRIES ABOUT CHILDREN  
WITH DISABILITIES INCLUDED:

bullying and teasing, and

keeping the children safe and well.

### 3.3 Supports for Families of Children with Disabilities Living on the Lands

#### 3.3.1 Who is Helping Families Look After Children with Disabilities?

When families were asked who was helping them care for children with disabilities, the overwhelming response was to name another family member or refer to the family in general. One person mentioned a friend with a washing machine. A number of families mentioned receiving goods and respite through a service provider and a few talked about the school and the clinic.

#### 3.3.2 Practical Help

Family members asked for practical help - food, bedding, clothes, washing machines, TVs and games for the children they were looking after:

*Sometimes I can't bring her (to get breakfast at an agency) because I might say, 'Do you want a shower?' and she'll say to me, 'No clothes, mummy, I got no clothes'.*



*She doesn't get blankets and mattress or anything.*

*They gave me help with different things, when he was just a little boy. They used to give me blankets, different things, toy, pillow. It was good, and he was looked after.*

An Aboriginal education worker talked about the practical care children with disabilities living in a remote community need, but may not always receive, from their families:

*Some kids are mental - and no carer for them. They need support, you know, they need somebody. (Families) don't cook their (children's) lunch. They never cook dinner. The children need somebody to cook for them. They need, 'Oh, here is your lunch. You can take it home and have it there, and then come (back in the) afternoon for your tea. You can take it for your tea tonight.' Like that.*

Many families were struggling financially and not receiving any extra assistance, such as the Centrelink carer payment. The mother of a boy with a disability asked for help *'to get him on disability money, carer money'*.

A family member, who was not receiving a carer payment, talked about the difficulty of managing financially:

*Yeah, sometimes it is a real issue, because it is expensive, and the food doesn't last a week with the amount of people in my house. And my partner gets paid fortnightly, and I get paid weekly. But it is still hard, because of payments of rent and car payments and all that sort of stuff.*

Sometimes the carer payment or family allowance was going to another member of the family who was not currently looking after the child. Changing the payment to the current carer could be difficult to negotiate because of intra-family relationships and Centrelink timelines, as this aunt looking after her nephew and niece, both with disabilities, explained:

*That's a bit tricky with the family, and it is hard, because then they'll expect me to take her on board (permanently).*

### **3.3.3 Specialist Services**

Families reported a lack of specialist services, such as physiotherapy, speech therapy, psychology and day-to-day support for people trying to care for children with disabilities on the Lands. Some family members asked for disability-related help for the child they were taking care of: things like an operation to fix a child's hearing problem, more speech therapy or extra help at school. A worker commented: *'I know that ... the rehab specialist has generally not seen our remote disability clients'*.

A mother talked about wanting help for her teenage daughter:

*She talked to me and told me, when she was a little one, 'I want to go and get my ears fixed, in town, appointment', but the doctor didn't send a fax for her appointment. And sometimes we miss them (the appointments).*

Several people asked for hearing tests to be done at school. Another woman asked whether her son *'could be taken to town and get a therapeutic exercise program?'*

A worker from the Lands expressed concern about the lack of services available on the Lands:

*The NDIS makes lots of talk about, 'Oh you people get choices'. There's no choices for people*



*here... They're stuck, you know. If they don't like the service that I provide, they can't look around and look for somebody else. There isn't anybody else.*

Accessing specialist services in hospital was difficult for children with disabilities and the family members supporting them. While the closest community is 250 km from a regional hospital, most are 1,000 km away or more, and the major city hospitals are even more distant. Two families commented:

*I have been talking to the clinic. And they saw him and had to send him on the plane to (the regional centre) and he had a check-up there and an X-ray. After that, that was his first flight, so he came back with medication. When he came back home, he was just going on and on for a long time. And every year, they always make him go to the city for his appointment.*

*We had to keep an eye on him at night and all, but we kept on making sure he take his dose of medicine. Medicine all the time. All the time. And after that big operation the other year, he had to go back every time ... for a check-up. We were all taking it in turns. I would take him, then the mother, and the father, the whole three of us, we were taking in turns, taking him to the city. Yes. That was a really big thing.*

Although some family members wanted more medical and therapeutic services to be available on the Lands, others were focussed on their more immediate needs, as discussed above in the section on practical help. Workers reported that often people would not engage with therapeutic services when they had worries about where their next meal was coming from or finding a safe place to sleep. Two workers explained:

*We're not hearing from families because they don't know how to request it, or what they should be requesting, or it's at the bottom of that priority list, because it's just about day-to-day and finding food and shelter or being safe.*

*Trying to get ongoing therapy for kids that need it has been very, very difficult. A lot of these people out bush, they are coping with things we don't have to normally cope with - overcrowded housing, people coming and going, plumbing that doesn't work all the time; all of these things that make caring for anyone more of a challenge than it does for us.*

### **3.3.4 Respite**

Family members frequently requested respite, both day respite and longer breaks - either to take their child out of the community for a while, or to have the family member who does most of the caring leave the community for a break. There are no organisations in the community to care for a child while the family gets some respite. An Aboriginal education worker from the Lands pointed out that:

*Mother or father must be having stress or - worry too much, 'Oh no I need a break. I need to have a, like...', no pressure for them, you know? You put more pressure and they'll get, like, sick, or like, some people get sick, you know? They get pressure, pressure, pressure, like, stressed out. They'll get blood pressure high, sugar high or low - and the brain's really, like, too much thinking, thinking, thinking, worry, worry, worry - bust the brains. Blood to the brains pop and then they'll get sick. And then who going to look after them?*

Respite is difficult to organise for people looking after a disabled child, as the option of placing the child in a regional centre with a strange carer can be problematic. There is, in any case, limited service capacity in regional centres and cities (all at a considerable distance from communities), and



24-hour one-on-one respite is expensive. A worker pointed out that, *'If you do it at six weeks in one year, it was like \$60,000.'*

One organisation was able to facilitate some medium-term respite care (with other family members in a different community) and day respite for family carers, and their workers commented that:

*We did assist the young teenage boy to go to (his) family in another community over the school break. That was a few years ago now though.*

*If we have time, (we do) some day respite stuff. So, doing bush trips, taking them out to dig for honey ants or witchetty grubs or cook kangaroo tails.*

FAMILIES ASKED FOR:

practical help with the basics (food, bedding, clothes),  
respite: having a break, and  
some medical and therapeutic services.

The main support was family.

### 3.4 Schooling

Many families mentioned that their children loved going to school. Several people made a point about how regularly their children with disabilities attended school. This was despite concerns that those children were falling behind in their learning and being bullied or teased by other children. In general, the school was considered a helpful and supportive environment.

Families whose children received extra help or support at school were appreciative. Two families pointed out:

*A lot of kids with that sort of problem, they left school, because they didn't have help. That sort of help. But, for my kid, while he's little, I am going to get him help, while he is growing.*

*Her teachers help her and they make sure she gets to the clinic for check-ups and to look at her ears. And they use a little hat with the hearing aid on... but sometimes she gets a little bit ashamed. She gets embarrassed about it.*

Not all children received adequate help in school. A grandmother was disappointed because the special teacher employed to help her grandson had left after a short while:

*We had to get a special teacher for him, but that teacher didn't stay in the community for very long. She just nicked off, and I felt really sad, because we were expecting that teacher to stay a bit long and learn him a lot.*

Several families felt that their children with disabilities were not receiving enough support in school and requested specific supports to improve their children's learning:

*Just her behavioural stuff; she needs a lot of help with that, and also ... if there can be more one-on-one, while she's at school. But not take her out of the class where she can just be by herself.*



*They got no extra workers there. They are trying to get one but they are worrying about money, money ... a speech pathologist and for doing signs (sign language) for them (would be helpful).*

*I was going to talk to the principal there... they are going to try to organise something for her. They need a teacher (for) speech (therapy). Every, like, Monday to Friday. And probably they'll learn a bit how to speak.*

Many specialists and therapists access children with disabilities through community schools. Issues, such as privacy and the rights of the individual or family, have made communication between services and schools more complex than they previously were. A nurse explained:

*Once upon a time, as the health service, you would go into the school and you'd be welcomed as a nurse and you'd talk to the staff and you'd talk to the kids and you'd grab whatever kids you wanted because you had a specialist visit... Now you've got to have a bit of paper signed to say you can bring that child. But, on the other hand ... those teachers will come up and want information from the clinic and the clinic will say, 'I can't give you that information. You've got to go through the right release-of-information system'.*

Visiting therapists often relied on teachers to carry out the programs they had developed for specific children, and to maintain equipment, such as hearing devices. Some therapists reported that this approach was difficult for some teachers with limited time and resources:

*From the occupational therapist's perspective, if you put out a plan for a kid ... and then the teacher doesn't pick their plan up, nothing happens.*

*So, that doesn't make me (the therapist) feel good about my job, because the teacher's not taking my recommendations. They're not implementing anything I suggest because they say they're too busy. I can't always even get a meeting with the teacher. (They'll say) 'No, no. I don't have any time.' I'm like, 'Well I'm only here for today. Or this week.'*

However, at other times, this approach worked well:

*The teacher in the class was interested in trying things... and then the preschool teachers are also really excellent. So it (the process) was (about) trying to support what they were doing, because I thought they were already doing amazing work anyway, for all the kids. It benefits all of them. ...and maybe just say, 'Oh well, you're doing everything I can think of that's good'.*

#### SCHOOLS:

Family members say that children generally enjoy going to school.

Schools were often helpful, but sometimes under-resourced.

Therapists often relied on teachers to carry out therapeutic plans and maintain therapeutic equipment.



### 3.5 Co-ordination and Collaboration Amongst Services on the Lands

Workers pointed out that inter-agency collaboration and co-ordination was crucial to the provision of effective support for children with disabilities on the NPY Lands. When this was lacking, the provision of services was affected, as these workers commented:

*The school has got more support, it seems, for children with disabilities and there seems to be more being done for those kids. But it seems like a lot of the service providers' programs come in and work at these little vertical program models and they're doing something and then someone else is doing something. And someone else is doing something ... and are we all talking to each other?*

*For some reason the school and the clinic, at that time, just didn't want to have anything to do with each other...*

Poor co-ordination of supports and services can affect a worker's ability to make contact with children. A lack of planning and co-ordination between visiting specialists, families and schools can reduce the effectiveness of the specialists' fly-in-fly-out visits to communities, as one worker pointed out:

*Four paediatric kids that needed to be seen are not there because the kids have gone to the swimming pool today. There's not necessarily a great co-ordination, in my opinion, of the services that do even exist, which are limited.*

A speech pathologist pointed out the necessity of inter-agency collaboration for referring children for services:

*It's that communication between the service providers, because the families aren't necessarily going to initiate and engage services on their own... Maybe it's that clearer understanding of each other's roles... getting that relationship to develop between the service providers so that they can just pick up the phone and be like, 'Oh, hey, so this has happened with this person. Is there anything we can do?'*

### 3.6 Diagnosis of Disability

Workers reported on the significant challenges in accessing appropriate diagnostic supports and services. Diagnosis is often essential to properly plan and implement development and support programs for children with disabilities, either on or off the Lands. Some funding of supports is also diagnosis-dependent.

#### 3.6.1 Lack of Specialists Visiting the Lands

The lack of specialist services on the Lands means that very few children with disabilities have an official diagnosis of their disability or its cause. A worker pointed out that '*I don't... think half the kids I work with even have a diagnosis*'. Another said, '*There's not necessarily a diagnosis for anything. It's just assumption, I guess*'. Other workers gave more detail:

*And also getting a complete diagnosis, because the visiting GPs won't (give a diagnosis). They might say 'suspected', 'possible', 'probable', 'likely', but, you know, to diagnose autism, you might have to have an OT assessment, a speech assessment. So that doesn't happen...*

*For the children with autism, it's very hard to get that diagnosis whilst living on community, 'cause of access to the paediatrics; but more so, access to the allied health component and also the overlap. ... Many of these kids have got social and behavioural kind of difficulties. ... is it*



*autism, or is it environmental, or a cultural issue, or an English-as-a-second-language thing, or is there some trauma or abuse, or ...? So it's really hard for those kids to get that diagnosis, and that's something that I think is a frustration for the paediatricians who do go across border and do see these kids in community; getting access to the allied health assessments so they can make that diagnosis and to get those kids support.*

Allied health professionals, such as this speech pathologist, were frequently asked to provide diagnoses:

*...a lot of the diagnosis... gets referred to our team and ...that's not our specialisation, so we're more likely to be able to go in and provide them advice for what the school can do differently, but it's on observations. A lot of the time, what schools want is a diagnosis so they can apply for their funding and then they'll do what they want. So that's a bit of a sticking point as well, that a lot of the referrals that we get seem to be for diagnostics, and that's not our strength at all.*

### **3.6.2 Cultural Appropriateness of Assessment and Diagnosis**

A further complication is the lack of culturally appropriate tools for performing assessments and making diagnoses of children with disabilities. This is particularly so in relation to speech assessments, where language differences inhibit the understanding of a child's language development. Language also affects other assessment areas, as workers describe here:

*...You can't do a standardised assessment that way, because that's for people who speak English as a first language. So it's been hard that I couldn't, with children specifically, I couldn't get ideas necessarily, for how do I find out their language skills? I mean, I can find out their skills compared to a native English-speaking child... but how do I know how they're going, related to their peers?*

*We have this assessment called the Renfrew action picture test, which is ten pictures where you talk about some kind of picture description-y sort of task and some people have changed it and put in culturally appropriate pictures, things that might actually make sense to kids who haven't come across whatever was in the other pictures. So some of those pictures have been changed, but, again, it's not standardised, so the information they're giving you, they can't compare it to that standardised assessment form.*

*I've just been approached about how we do the ASQ (Ages and Stages Questionnaire) and an ASQ Start, and the reality is that the ASQ that we have is very non-specific to the culture that we work in. So even the tools that we do have are not terribly effective.*

A speech pathologist pointed out that often specialists do not have access to interpreters:

*We don't get interpreters. Didn't tell you that one. So we don't have access to interpreters, which would be useful. That would be like number one.*

### **3.6.3 Diagnosis to Fund Aides in Schools**

Schools require a diagnosis of disability in order to apply for funding for additional assistance, such as teachers' aides, in the classroom. An allied health worker gave an example:

*See, the schools are saying, 'We think these kids, they've got FASD (Foetal Alcohol Syndrome Disorder), but we're not absolutely sure'. My (allied health) staff come back from some remote school saying, '(the) kid's just jumping off the walls'. The schools are saying, 'We need more resources'. The education department is saying, 'Look, just pretend, just act as if they do have*



*FASD and put in a program. Don't worry about the diagnosis'. Yeah, so they put in a referral, and I come in and I say, 'Hey, so what's the problem? What do you want?' They're like, 'I need a report so I can get funding, so I can get another teacher's aide. I need you to write a report to tell me that this kid has problems, which I already know, so that I can submit it to the Department of Education, so that they will say, "Yes, this kid has problems. I'm going to give you extra money for a teacher's aide"'.*

### 3.6.4 Accessing NDIS Services

Workers pointed out that under the Early Childhood Early Intervention approach of the NDIS, children up to a certain age can receive services based on a functional assessment, rather than a diagnosis. Potential entrants to the scheme over six years old, however, need to enter via an 'early intervention' category and use that first year of their plan for diagnosis and assessment. This worker from the Lands explained the eligibility process for children on the Lands:

*You can go under global developmental delay 'til the age of six and then, after that, it gets a bit harder for services and schools to get one-on-one funding...*

*We had the Early Childhood Early Intervention funding and we were able to get quite a number of kids (into the NDIS) on that because, under six, the NDIS weren't worried for a diagnosis. It was a functional assessment, which we could get teachers or the preschool people to fill out, and then the doctor to complete the form with all the information coming in from all the people that were involved. But what would worry me now is when they turn eight they'll be exited, because there still won't be a diagnosis, because there's not the appropriate services registered yet.*

#### DIAGNOSIS OF DISABILITY:

Many children don't have an official diagnosis for their disability.

Diagnosis is needed for supports: for teaching aide positions in schools and for children over the age of six to become NDIS participants.

The lack of culturally appropriate assessment/diagnostic tools exacerbates the difficulty of diagnosis, as does the inability to work in the child's first language.

### 3.7 Early Childhood Early Intervention (ECEI)

There were limited services providing ECEI in the Lands and those that did exist depended on the continuity of adequate staffing. One team that was giving priority to early childhood (under school age) early intervention had a long waiting time for certain services:

*For speech and OT, an early intervention is probably about a 12-month wait.*

Many communities across the NPY Lands had preschools and playgroups, although some were not operating due to a lack of staff. Several communities were also taking part in the Families as First Teachers (FaFT)<sup>6</sup> Program. Workers expressed their concern about ECEI services in some communities:

*There are also inconsistencies between communities on the Lands, within and between States and Territories. So, one community has this big fancy great thing. Another community does. Other ones don't, so there's no consistent approach to children and to early intervention and parents getting, having a good understanding of early intervention as well.*





Another issue for ECEI service providers is that many families do not want to engage with the services that are available. The National Disability Insurance Agency (NDIA), which administers the NDIS, funded a worker for a year to work proactively with families and encourage their engagement with services and with the NDIS, but that position was discontinued.

EARLY CHILDHOOD EARLY INTERVENTION:

There are limited services available on the Lands.

### 3.8 Reluctance to Engage with Services

Workers reported that families were often reluctant to engage with services. One worker commented that *'people don't engage so much with the mainstream services'*. Some of the issues mentioned here have been referred to in section 3.2.1. above. They are included here because they are also key factors in Anangu not engaging with services.

#### 3.8.1 Shame

Shame can lead to a reluctance to engage with therapeutic services. The cultural unacceptability of standing out from the crowd meant that people were often ashamed to ask for services or therapeutic aids. For example, a grandmother talked about her family's shame in relation to a child wearing glasses:

*Yes, he can't see. He had glasses before when he was a little boy, but the dog grabbed it and chewed it up and I asked the doctor if I could have another glasses. But the family said, 'No, don't give him any. He make us really sad.' Yes, that's what they said, and so I left it. Didn't ask or talk to the doctor about it.*

Several workers referred to shame as an issue in relation to accessing services:

*If you think you're different and getting services, that potentially can equal some shame for some people.*

*The grandmother will tell me, 'Oh no, it's the shame thing'. I have had a few families say, 'No, oh, no. He doesn't want to shame!'*

In addition, fear of blame and cultural punishment for something being 'wrong' with their child makes people reluctant to acknowledge a child's disability and pursue therapies, as this worker pointed out:

*Family are really quite cautious as well around children having disabilities, (worrying) that they're at fault.*

#### 3.8.2 Living Day-to-Day and Having Other Priorities

Many families do not plan for the future. A senior woman from the Lands explained, *'in our culture and custom, we don't really plan for the future'*.

Rather, Anangu focus on the present and on immediate issues, such as where the next meal is coming from, ensuring they and their family have bedding, clothes, and a safe place to sleep, as well as fulfilling their immediate cultural obligations. This was clear in the requests people made



for assistance, described in section 3.3.2. Living in the present in this way affects people's abilities to consider the long-term outcomes for their children with disabilities. Workers explained how this affects service access:

*What they want, they want meals, they want different things that help them to sustain the caring relationship out bush.*

*There's different priorities and it's hard to look into the future. For some of these families, it's hard to think about, you know, in 2 years, what their child will be like.*

*Sometimes therapy is not a big priority. Like, it's not ... and that's something that I didn't know when I first came, ... how many other issues are going on for these people ... and that sometimes having physio is right at the bottom of the pile.*

The lack of planning can have longer-term consequences for children whose therapeutic needs are not prioritised in their younger years. This worker spoke about problems that may arise as a result, when the child becomes older and larger:

*It might be okay 'cause the family can pick up the child and carry them around, but when that child grows and they're quite contracted and they're quite difficult to move... we've kind of missed the boat, but ... it didn't look like a priority to the family ... And they're some of the things that, in the long term, may make it more difficult for that child... You know, if a child with cerebral palsy isn't supported and positioned well from a young age, they develop contractions. They develop a bad scoliosis and, all of a sudden, there's all these medical complications because of that scoliosis, and now they do have to live in town.*

The fact that Anangu generally do not plan for the future is a key issue for organisations working with children with disabilities on the Lands, and some service providers expressed concern about how this would fit in with the way the NDIS works:

*Under the NDIA model, it's all about families setting goals and priorities for their children. Just thinking about some of the difficulties that the family has had in setting goals, because the family itself has been just in crisis mode so long and so even a simple thing like ... a stable environment or a stable situation for these children, is so important. And sometimes, with our families, that doesn't happen, or it takes a while for that to happen. I know that this is something that ... I think that NDIA will have to put up with ...*

*I think, with the NDIS, it depends on how flexibly they can write the plans. The plans that I've seen written have been about getting a therapist to see them ... When everything else is going well, you then would get some benefit from a therapist, but these plans have been written assuming that the therapist is the best input to start with. I think there's a whole lot of other issues and people that can be involved at a starting level to make sure that their foundation is more intact.*

### **3.8.3 Worker Relationships**

Anangu need to build trusting relationships during their interactions with other people, including workers. They are much more likely to engage with services when they know and can relate to the workers. One worker gave an example in relation to ECEI services:

*When I talk to them and say, 'Well, why aren't you going to Families as First Teachers (FaFT)<sup>6</sup> or childcare?' (The response is), 'I don't like them'. Whereas, back in New South Wales, that*



*wouldn't be the big issue that stops you from going.*

Anangu consider that direct questions are impolite, so establishing a close relationship with families allows the worker to build up an understanding of each situation and any issues and to minimise offence. A senior woman from the Lands explained that *'you can't ask straight-out questions ... take time and patience, get to know that family to ask them questions ... not straightaway'*.

A close relationship with Anangu is not possible for workers when they are only visiting communities once every few months, or when there is a high turnover of staff, as these workers explained:

*So the relationship building's really important. So it might take us a really long time to even get to a point where they'll say, 'Yeah, hey, I might need a little bit of help with this'. Then when you take someone else along, they'll say, 'No, there's no problems'. So, that was a big thing with the NDIS. When the planner would go out, the parents will say, 'Oh, just a bit funny with how they eat'. But previously, they've spoken about other concerns and worries and difficulties that they're facing.*

*We had the challenge of trying to find a time to work with them. Because we'd turn up at the house at the organised time, they wouldn't be there. We'd call. They'd say, 'Oh, I'm just down the street. I'll come back later'. You can get around that when you're in a town and they're only five minutes away... If I'm like, 'Well, okay, I'm out here for a week, how about I come back tomorrow?', it's so hard to find them again. Sometimes they'll just be gone. They'll go to a different community the next day, and I'm like, 'Oh, all right. Well, I'll try and catch you in six months when I'm back'.*

This family member expressed her satisfaction with the workers and teachers who had supported her son for several years on and off the Lands. For her, and for many Anangu, this is the right way to work:

*They kind. They never change. They always love him. Yes, they know everything. Even Culture Centre, even this shop. Yes, they know him from little.*

The mother of a girl with a disability gave advice along similar lines to workers:

*'Speak good to young children. Don't be nasty. Don't raise your voice. Be calm when you speak to them. You sit down low and straight and level with them, yes, and then cuddle them and comfort them, and then you just talk to them in a good way. Can you do this for me please? You know? You make me more happy.' And all that.*

Anangu expect workers will listen to them, *'talking and helping along, all the way'*, and respond to their requests and needs, as one woman specifies here:

*Just sit down and listen to the family, to the patients. If they are saying there's something wrong, then listen and find out.*

### **3.8.3.1 Staff Turnover Issues**

Workers in service provision organisations talked about how long-vacant positions and high staff turnover were common issues affecting service delivery, as these examples show:

*And in the NT and Western Australia, I dunno about South Australia, quite often visiting services aren't available because of the staff turnover.*



*And just look at the turnover. The turnover of remote community services is pretty high ... Most of the people I know that've left, it's because they're sick of ... not being able to work the way they think's effective.*

*We've spoken before about high turnover of staff and that's not just direct support staff, that's our co-ordinator, management level. Even clinical teams and things like that, they've turned over - must be on their third go in 18 months.*

High staff turnover rates not only affect the level of engagement of Anangu with services, but they also mean the loss of expertise and understanding of remote work within services. Workers commented on the impact on service delivery:

*With that high turnover, you lose so much knowledge, when you've had a staff member working in the site for 18 months, two years...*

*These visiting specialists, they might see someone and then, on the next rotation, two months later or whatever, it's a completely new person, so Anangu don't necessarily always like being seen and poked and prodded by a completely different whitefella 'that just tells me I need to take some medication that I don't want to take'. So I think that plays into how services are provided and received.*

One worker cited the situation of a teenager who wanted to return to the Lands, but:

*In terms of a case manager at child protection, he's had hundreds, and they'd ring and they'd say, 'Oh, we really want to get him home this year'. Year after year, a new case worker would tackle it once, and leave. You know... no one's staying in their job, so to me, that was one of the main reasons for this failure.*

Workers also talked about the difficulty of recruitment. Some workers were concerned that the rollout of the NDIS might exacerbate the difficulty of recruiting staff to remote positions:

*We've had a few OT (occupational therapist) adverts and we found it very, very difficult ... even to get people that have got two years' experience, let alone five or ten. I think for people that have not got that clinical expertise under their belt yet, they work for a year or two and think, 'Oh, I'm losing skills. I really just want the nuts and bolts'. So that's been a real challenge for us.*

*What worries us at the moment is that, as the NDIS starts to get traction around the rest of the country, ... there's probably plenty of work out there ... The competition is really ramping up, so people don't need to come (to the Lands) unless they really want to.*

Some workers suggested the development of a disability support workforce comprising Anangu workers. Local workers would already be on the Lands and living within traditional culture and society. They would often be in a better position to work with local issues, as illustrated by an Aboriginal education worker:

*We always talk to the kids not to tease a mental person. They are mental. They don't know this world. They are in another world. That's why we always explain to the kids, talk about them and they know they don't tease them. They respect them.*

Workers from service organisations explained that recruiting Anangu would require intensive



support and supervision. For instance, some people from the Lands do not have a bank account or birth certificate. Potential workers need a high level of support to obtain police checks and other clearances for working with vulnerable people, which can be a lengthy and complex business. A worker pointed out how this process would work:

*Generally, you start with Centrelink and say, 'send me a health care card'.... Things start with a Medicare card. Some might need support to even register for a Medicare card... so there's quite a journey.*

Aṅangu would also need support and supervision in order to keep them engaged in employment. Work represents a significant departure from the traditional lifestyle of people living in remote communities. One worker commented that *'the idea that you'll get up in the morning and work nine to five, five days a week; it's not a value that's really embedded here yet'*. Cultural issues might necessitate the development of an appropriately flexible working model. A worker pointed out that *'There is some people that can't work with that family because it's culturally taboo and all that kind of thing.'*

Other cultural factors, such as the need to prioritise family matters over work commitments and the desire to maintain a mobile lifestyle, can affect people's ability to maintain a permanent job. Some organisations, restricted by their industry enterprise agreements, respond to this by employing people *'only in a casual capacity'*.

#### ENGAGEMENT WITH SERVICES:

Families of children with a disability often don't engage with services for a number of reasons including: shame, more immediate concerns with basic needs, and unfulfilled expectations of building relationships with workers, partly due to short, infrequent worker visits and worker turnover.

### 3.9 Cross-Cultural Issues

A number of cross-cultural issues have already been touched on, such as Aṅangu having a need for trusting relationships with workers. Several other differences between the Aṅangu culture and the Western mainstream culture affect workers' roles and ways of working.

#### 3.9.1 Parenting and Living Styles

In remote communities, responsibility for a child does not always or solely lie with the child's parents, but rather is shared amongst family members. This can be confusing for service providers, as this worker explained:

*We white Western services, we always think that it's the parent, the mother and the father that has the say, but out here, culturally, it's very important what the grandmothers think and what the aunties think.*

Workers often have expectations of people from remote communities based on their own cultural background. Parenting can be a fluid situation for Aṅangu<sup>7,8,9</sup>. For example, two of the children



discussed in this research appeared twice, living in different households over the period of the interviews. A therapist visiting the Lands to work with a particular child commented:

*One child ... would be living with a different person each time we arrived, so it was hard ... to keep relationships with all the right people ... and then just finding them when you get to the community and pot luck that they're there and you can also have the time and space to do any work based on whatever's happening in the community at the time. But even if you're aware that there's going to be issues, having someone that's on the ground regularly, it smooths the way; it's essential really.*

Some aspects of Anangu child-raising are different from Western parenting. Children are expected to learn through experimentation rather than having set boundaries, and spend a lot of time with other children of a range of ages. A worker said:

*Parents don't play with their children; they don't engage with their children the way that they would in town or wherever. They don't ... Often the kids will grow up and they'll be looked after by the other children.*

A lack of understanding of traditional child-rearing practices can create problems when therapists expect parents to oversee a therapeutic program. Therapists have expectations of parents that may be at odds with the traditional ways of raising children on the Lands. Some therapists' requests appear embarrassing and even shameful to parents. One therapist gave an example:

*So, I'm trying to talk to a parent and say, 'Hey, how about you sit with your child and read a book together and play games with them?'... If I say, 'Do you ever do this?' They'll say, 'No.' For one, they don't have books in their house. But if I'm trying to find other things... you know, I can see a ball on the ground. 'How about we work on how you can use this ball to engage with the child?' Then I generally just get the, 'Yep, yep, okay, yep' sort of answers from them... It's been quite tricky, because often I'll want to model the therapy, kind of, and get them to have a go ... But I don't think I've had even one parent who's had a go. They're just like, 'Oh no!'*

A dietitian commented:

*And I think any parent has that issue with how much do you persevere with trying to feed a little bit more, versus you don't want to force-feed them. And how much of it is really important? But for some people... the child doesn't want to, they don't want to push it and they'll leave it alone.*

Lifestyles on the Lands mean that worker expectations around families adhering to a specific feeding regime for children with special dietary needs can be difficult for Anangu. When asked what factors made special feeding for children on the Lands successful, the dietitian quoted above spoke about adapting to the mobile lifestyle on the Lands:

*I think keeping the feeding process simple ... (and ensuring) they've had the support to have the feeds in various locations, so when they have moved around, there's been something that they can access.*

Another person who works with children on the Lands explained:

*When you actually spend time in a house every day, you realise that what's in the fridge is a great big lump of cooked kangaroo and absolutely nothing else. So when you're asking them to cook for their child, it's not like they're cooking for their family. They're eating bread and tea and*



*kangaroo all that week, say, and, some other time, goodness knows what they're eating, and occasionally she [mother] might make a stew. But to have this food on hand three or four times a day to feed this child ... they've never expressed it really, but it must have been, 'Why are we doing this?'*

### **3.9.2 Beliefs About Disability**

Anangu have a culturally based view of causation and recovery from physical and mental illness. 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 messages. A worker commented:

*You can talk ... until you're blue in the face about why you need to sterilise equipment, but that's a Western health model and doesn't always fit with what their understanding is.*

*(In town), there's an orthopaedic surgeon; there is a rehab specialist that comes for the paediatrics. But a lot of our clients don't go, and I think part of that is that no one has ever explained to them what the benefit of seeing the doctor is....to help them understand why it would be beneficial. ... If you don't know what it's for, and you have to pay for it yourself and it's going to be a bugger to get your accommodation...*

Many Anangu have difficulty understanding the extent and implications of the disabilities affecting their children. Some families hoped or expected that their children would recover as they grew older, as this statement by the grandmother of a child with cerebral palsy illustrates:

*He has got a lot of things that has happened to him. Too much. And we are just wishing and hoping that he will walk again and speak! ... Nobody telling us that...just hoping. But we don't go and listen these days. They are busy and they are flat out, you know, with all these other... I don't know who we are going to listen to ... to find out the story ... what's happening...*

A worker expressed this as, *'that sort of blind hope that he would grow out of it'*.

### **3.10 The Future for Children With Disabilities on the Lands:**

#### ***'For the future, I need help'***

When families were asked how they saw the future of their children with disabilities, they expressed ideas about the children 'growing up strong'. Most families mentioned the benefits of education and hoped their children would continue to attend school. A woman said of her daughter, *'I just want her to go to school like every other normal kid'*, and a father thought he wanted his son, *'Seeing as he loves football, probably for him to play football when he grows up'*.

Several families suggested that their children might go away to a boarding school:

*I want to see her future, like, one of learning and getting plenty of help and support from white people and to learn. Send to school, like boarding school.*

*She's always talking about going to Adelaide. ... she want to go Christian school. She'd go with a friend. ... She might get more help.*

*Take him to school. Put him in school. When he gets a bit older, send him to a, like, private school*



*... Long way from the Lands. They have got better schools... More help for him. I told her, 'You got to go to school. High school. To learn more. You look after your grandmother, you help her and clean for her. You keep things clean...'*

One proud mother had definite plans:

*He would like to go away, yes. Go and do more education in (the city) ... must be, because he's getting a really smart boy. The schoolteacher says to me ... One or two from another community, and him and someone else from here, too, are going. Yes.*

Another family suggested that a boy might need to leave the Lands to get his care needs met:

*When he gets older, she (his mother) might send him and white people can look after ... because he's too much work and she worries for him.*

When the mother of a child with a disability from the Lands was asked about the future, her reply summed up what many Anangu said: *'For the future, I need help'*.





## 4 FINDINGS: CHILDREN WITH DISABILITIES LIVING OFF THE NPY LANDS

Almost a third of the children with disabilities discussed by Anangu in this report were living off the NPY Lands. They were living in cities or regional centres, such as Perth or Alice Springs, where care and therapeutic services were available. Some were in foster care, some in institutional care, and three were living with their families, who had also moved into town.

Families not living with their children often had limited or no contact with them and generally had no idea how to negotiate the mainstream system to arrange visits to see their children. Discussion with families and service providers suggested that there were many children in this situation.

This chapter looks at the reasons given by families and workers for children leaving the Lands, and at the main issue raised by Anangu, that of the loss of contact between families and children. Families who had moved to town to support their children with disabilities are discussed in the last section of this chapter.

### 4.1 Reasons Why Children with Disabilities Leave the Lands

#### 4.1.1 Lack of Supports and Services

Looking after children with disabilities is difficult for Anangu because there are so few supports for these families on the Lands. A worker pointed out the need for people to have case management and/or advocacy help to assist them to negotiate the support system. Two workers commented:

*It's very hard for those mothers to keep those children in community. They just about need a full-time disability support person in the community helping those mothers so that they've got that contact and that place to go.*

*See, I realise that the parents have come to the end of their rope and they can't look after the child, but that doesn't mean they don't want to have anything to do with him. There simply aren't the facilities for these people to be supported out here.*

##### 4.1.1.1 Daily Help and In-home Support: 'There's no one out there to do it'

There were no in-home support services on the Lands providing help with bathing, lifting or feeding children with disabilities. Domestic assistance, available in some communities, was for laundry and, in some places, a meals-on-wheels style service was available for a fee. There were limited community respite options to provide a break for family members. Workers on the Lands spoke about the lack of support for people looking after children with high-care needs, which led to many children moving away from family and community:

*The support that families receive is quite minimal, when you think about it, to support people with disabilities in their community ... So therefore, people (children) are getting removed because of their inability to care, or their lack of support in the ways in which they ... can care for these people. So I think there's a lot of contributing factors as to why these people with disabilities are ending up in our care - which could have been intervened quite a long time ago in their home communities and the money should be going there rather than here...*

*Because, if those children lived in either a regional centre or a city, the system, whether it's us or NDIS, would be able to put appropriate supports into the family to assist them. But we can't*



*do it out bush. Well, we haven't been able to do it yet. Not even 24-hour, but it would be good, particularly as kids get older and they get heavier to lift..., daily supports going in to support transfers. You know, you could put someone in there, or a couple of people in there for several hours a day, or a few hours a couple of times during the day to support parents with the care of the child ... when they're heavier and older... We've always found it really difficult out bush... there's no one out there to do it.*

*...younger child, permanently off the Lands last year, ...PEG fed (fed by percutaneous endoscopic gastrostomy, via a tube, usually directly into the stomach), feeds weren't going well, getting bigger, ... we didn't have all that sort of special equipment in the house and so it was getting hard for mum ... she was a very young mum to be caring and lifting. ... lots of love in the family home ... It was just hard in a lot of other ways, so he's off the Lands.*

Another worker spoke about a woman who was unable to continue caring for her daughter:

*So, what happened was that she just couldn't access the kind of respite and support and care that she needed to access to keep going, and what she decided to do was - the child had to go down for a medical procedure to a hospital in the city and she decided to abandon the child there.*

A father talked about the lack of support for his child, the decision to give her up and the loss for the family:

*Well, she was a weak baby and she was sick from meningitis, and we couldn't really handle her, because we had no money to help her properly, with good tucker and all those sorts of things, but we didn't get no help from anyone. That's why we wanted help to take her away and they did take her away. And since, we never saw her. And then she passed away.*

#### **4.1.1.2 Specialist and Therapeutic Supports**

As described in section 3, as well as day-to-day help and support, people lacked specialist and therapeutic support on the Lands. These workers pointed out the difference in availability of support services in town compared to in the communities:

*And the reality is that they will get more services if they're in town.*

*So these guys could visit him - speech, OT and physio were visiting weekly. Whereas, if they were living in the community, the remote team might visit there once every three months or something.*

Sometimes the suggestion that a child should leave the Lands came from service providers. When asked if the doctor had suggested her granddaughter leave the Lands, this woman replied:

*Yes, yes. That was after she was sick and went to the town. So they said, they decided to say, 'No. she no come back no more'. ...Yes, the doctor. So she was given to the lady and then people who are looking after them.*

A mother talked about her daughter being off the Lands:

*I said, 'No, I want my child back'. I sent her away when she was really small, because she was sick, and the doctor heard me, but the doctor said she will get better and getting older in that city after the operation.*



An education worker in town commented on the increasing number of children moving in from the Lands:

*I think it's (government department) actually doing their business, you know, going out to the communities and things like that because, since that's been happening, we've actually had quite a number of children with disabilities come in from communities.... I'm pretty sure they've always done that, but it's more ... the last eight years or so, it's been more: 'We've got this child at whatever community who's a potential candidate for attending the special school'.*

Many service providers were aware of the conflict between children's needs for family and culture (a source of emotional and social wellbeing) and the specialist, therapeutic and care service offered away from the Lands. This worker spoke about a child living in a remote community, before discussing more general issues:

*She seems to be very well integrated into the family up there. There's definitely cases where, the higher level cerebral palsy kids, if they had've been in town, their contractures would have been less, or various sorts of things. I guess that goes back to the difference of, what's quality of life for these kids? Is it being able to open and close their hand for no actual grasp or is it living at home with their family, and that sort of thing? And their parents get to decide. ... I'd be very reluctant to say that kids living out bush with disability have got the same outcomes as what they might have gotten in town.*

#### **4.1.2 Children with High-Care Needs: 'It's really hard for us!'**

Both families and workers raised the issue of Anangu struggling to look after children with disabilities, particularly those with high-care needs, on the Lands, where care support was limited or unavailable, resulting in some families sending their child to be looked after away from the Lands. Many of these children had very high physical care needs; for example, associated with cerebral palsy or similar disabilities. Some of the main people caring for the children were elderly, often grandmothers, with their own health issues. It became increasingly difficult for family members physically to lift or move children as they grew. This boy's grandmother was able to access some regular respite, but still found it was too hard to care for her grandson:

*Yes, white people were looking after him. They'd have him for two weeks. Then, other times he'd come back on the plane. Other times, he would come back on a Toyota. If they did that, they would stop half way. And sometimes we'd go to pick him up from there. I had him all the time. He grew up, and got bigger, but then I had to decide that it got too hard. You know, it is hard. He'd come back and go back and forth, but it was still hard, too hard for me, so I had to say to my daughter, 'Look, I'm sorry but I can't keep doing this. Sadly, I can't keep it up. It is much too hard work for me'.*

Another family struggled to look after a young girl, especially as she became older and heavier to carry or lift. Again, regular respite was tried before the child moved away. The grandmother explains:

*Her dad and mum were staying on the Lands when she was a baby. They were happy families living there and disability (service) helping her with, like, getting things for her, helping with paperwork, with food, things like that. But when she grew up really tall, she was too big, so a white woman took her on. She was staying in (a regional centre). She'd come home just for a while, keep her here for a while, and then she was just getting sick and sick, more sick, so she said, 'All right, she might go to the city.' So she went there....*



Another woman's grandson spent a lot of time in hospital in the capital city of the state (1,500 km away from his home community on the Lands) before he was taken into foster care:

*I was there with him, and it was a lot of trouble going on the plane in and out, go, come back. I was flat out. .... Me and his mother went and helped him. Looking after, go and sit down, you know, when he had the scan. He had to go for months, you know. And then, when the mother get tired, well, she come home, and then it is my turn, and then the father's turn. The main people were working very hard with him ... All that time he was in hospital... Too much. It's really hard for us.*

A little boy in the care of his aunt was unable to stay in his home community once his aunt became seriously ill. His grandmother explained:

*We couldn't... I was starting to get the (renal) sickness and I said to the doctor that the family would decide what we are going to do with him. And they asked, 'Do we want to send him away to a home where he can be well looked after and be well-educated?' And after that, they found a carer for him. His aunt couldn't look after him. She really sick, poor thing.*

A worker spoke about another family struggling to care for their son who had cerebral palsy:

*He'd be moving around and very unsteady and she'd say to me, 'When he grows up, he'll be all right, won't he? He'll get better. This won't... this is just for now?' They really didn't grasp it was forever, and I think when they did, the parents came into town, they brought the child in, they both got drunk, they got picked up, the child put in care and that's the beginning of the end. That's the signal that they just can't cope.*

If the child was a boy, it was culturally unacceptable for females to dress and wash him as he became an adolescent. One service provider said:

*(We) tried to work really hard with the family around keeping him there but, in the end, he was becoming a teenager and so it was inappropriate for his mum and his grandmother to be providing personal care for him anyway.*

A local Aboriginal education worker commented about boys with disabilities, that:

*They should have one bloke working with them, show them how to wash their body and how to keep clean. When they are having a shower, they are fresh and nice and clean person walking... That's the man worker to show them.*

Sometimes people became so frustrated by the child protection system in their attempts to place their child in foster care that, as a last resort, they abandoned their child at a hospital or similar place:

*We've had at least two cases of children with profound disabilities who the family's found themselves in conflict with child protection. Actually, not because the families were doing anything wrong; precisely because the families were good parents to these children and they needed more support than they could get, to live on the Lands. These children had very significant and very profound disabilities and, when they went to child protection and said, 'We need some help. We wouldn't mind having our kids fostered or whatever, but we don't want to lose our kids. We just can't give them what they need here on the Lands', child protection said, 'No, you're good*



*parents. We don't do that for good parents. We only take them away if the child is neglected or abandoned or something like that, you know'.*

A worker talked about the long process of supporting a woman to retain parental rights with regard to the child she was unable to care for:

*It's her baby, but recognising that (was a problem), because disability services offered the option that the mother wouldn't lose her parental rights, whereas child protection were holding the position that if they took over, the parental rights would be gone. The lawyer got involved and wrote up an agreement, which actually went to court. When it went to court and the agreement stated what the parents were entitled to, it kind of worked out okay on that occasion. It was a long and painful road. It took weeks and weeks of work. It took weeks of advocacy, weeks of sitting here with the parents and hearing what they wanted, of talking to agencies, of getting support.*

Some children attending a special school in town had no known relatives, as reported by a school worker:

*And a couple of those children, I have never heard anyone talk about their family. They're not listed as having family. I sense that they may have been left at a disability home or somewhere at the hospital.*

#### **4.1.3 Foster Care: 'It's better for him'**

Many Anangu felt that people in the cities could offer their children the best options for life, as these comments show:

*I think he is in good care, and a good school where he can get learn, and one day he might - when he turns 18, he might - come home.*

A woman living in a city with her grandson explained:

*I have been saying that I want white people to help me... Not Anangu. I want professional people. I want people who know what they are doing, who will do a good job, who will be reliable. People who will source money to look after the kids. The city is now our home... If I got ill, I would go to hospital, and what I would want is for white people to move in and look after the children. Not Anangu. Anangu shout all the time, make a lot of noise. They would all move into my place 'to help out' - but only in the future.*

When asked if she wanted mainstream carers to look after her grandson with cerebral palsy, another woman replied, 'Yes. Poor thing. Because he's too much (work)'.

Another said, 'That child is a cousin too. I think he's the same like my niece. But he grew up with good white people looking after him really well'.

One woman, whose grandson was in foster care, listed the benefits of life with white people:

*White people are okay. They can do everything... Toys and nice things... Washing machine for washing the bedding and blankets... Nice bedding... Looking after, giving baths... Nice clean faces.*

A different view was expressed by another woman, who worried that:

*Some whitefellas are really good, though some are really bad. We hear the news. We do hear*



*some terrible stories of carers murdering children. We hear of cruelty. So that's what we are frightened of too.*

At the same time, several people referred to Anangu (including members of their own family) as lazy. The interviewer reported that,

*some senior women spoke about the difficulties they saw if family members did try to look after children with severe disabilities themselves on the Lands. They said that their houses were not set up to provide the level of care that they knew was required. For example, they said their houses were overcrowded, hard to keep clean, often didn't have equipment, such as fridges, washing machines, furniture and cleaning equipment. Unhappily, they also said that they worried their own children were too lazy to do this work properly to a suitable standard.*

For instance, the grandmother of a child living off the Lands said:

*Mothers must be lazy. They might hit them or neglect them, out of not being able to cope due to no help. So that's why they said, 'No, they might give it (the child) away'. But we miss them.*

Another grandparent was concerned for her granddaughter with a disability because of domestic violence in the household:

*He (the father) might do something, you know. Something might happen, accident. Accidentally. So we can't give her to her mum.*

#### WHY ARE CHILDREN WITH DISABILITIES MOVING OFF THE LANDS?

Families find it hard to look after children with disabilities because of the lack of basic facilities.

There are no services helping with and supporting daily care, and there is limited provision of respite.

There are limited specialist, therapeutic support and care services.

Many people think children with disabilities will have better lives in mainstream care in a larger centre off the Lands.

## **4.2 Contact with Home and Family: Wellbeing of Children with Disabilities Living off the Lands: 'She is forgetting who I am'**

When children with disabilities move off the Lands, away from their homes and families, there is limited or sometimes no contact with family, the Lands and culture, and both the children and their families experience grief and loss. It is important for the wellbeing of both children with disabilities and their families that these relationships are maintained. One girl returned home to her family every school holidays and the workers at the school reported that she:

*...has quite regular contact but she is so attached to her mum that (it) is really traumatic for her when mum has to leave... (After the holidays), she comes back really upset... usually the first two days is the worst with her, emotionally, but then she gets back into being happy again.*



A grandmother explained about her grandson in care in town:

*Everybody misses him. He has a lot of cousins and uncles and they all miss him. They say to me, 'Oh we want to go and visit him and see how he's going.' I go but...he wants to see everybody because he misses everybody too. He asks us, 'Take me back with you.' And all we can say is, 'Sometime in the future, maybe we will.'*

#### **4.2.1 Children with Disabilities in Supported Accommodation**

Several of the children discussed in the interviews were living in supported accommodation in regional centres. Their wellbeing was dependent on the nature of the accommodation, often staffed by transient workers with limited knowledge or understanding of the culture or language on the Lands. An education worker commented:

*The small number of children who don't have family connections and have a churn of new carers going through their supported accommodation. They don't know ... who's going to care for them...*

*So, (they) have a range of different sorts of carers, from some that will just care to some that will go that extra mile to make life happy for them. We found that there are a lot of young men who are the carers for a lot of our children in care. We'll meet someone one week and we get to know them and then they're gone and then there's another one in a week or two... There is very little relationship happening there, so this (the school) seems to be the place where they feel like they belong the most. That, to me, is a real issue, that those children don't have a proper identity and they don't have regular carers who are able to be their de facto parents, and there's no one who actually loves them, except the people who are at school.*

Education workers commented that some children were moving back and forth between foster care and institutional care settings. Some children had bounced from one care situation to another:

*He was put into care, then he went into foster care, back to being placed into accommodation. Then he was with a carer, (then in) accommodation, and he actually got handed over to another foster carer, but for some reason, I don't know what the reason was behind that, but then he got handed back ... and put into supported accommodation.*

*I would say that is the most difficult situation, that they've been with a family and then suddenly dragged out of that and put into supported accommodation where you just have your workers...*

Not all children in supported accommodation lost contact with their families. A teenage boy lived in what a worker described as a 'house with two other young men who are also in wheelchairs. They have stable carers... everyone says it's a happy household'. He was not able to return home, a family member said, because 'it is too difficult, which is why we go to visit him there'.

Another suggestion from families was for the establishment of a staffed accommodation facility on the Lands for children with disabilities:

*We need something for disability. (A) building here in community, and workers, special workers to come and work here. Like the aged care, where old people are living. Similar to that, and something for the little kids, disability mob, for their future and for the family to look after here, when we have a building here, so we can bring them back to our Land, to stay here, and the carers might come and live with her.*



#### 4.2.2 Children with Disabilities in Foster Care: *'I just want to cuddle my son'*

Despite the instances above, very few of the children with disabilities who leave the Lands to live away from their homes maintain contact with their families or return home. Anangu were often overwhelmed by the complexity of the systems around the fostering out of these children and had difficulty negotiating and affording visits. There was limited support and funding for people to travel to visit their children. The comments below show that this was a common situation. Some families had completely lost touch with their children, while others only received birthday photos and snippets of news. Anangu wanted face-to-face contact. The father of a young boy living off the Lands expressed this as, *'I just want to cuddle my son'*. People struggled to keep in touch with their children and worried that their children were losing touch with their language as well as forgetting their families, as these comments indicate:

*A long time. No, I never seen her again, since she went with the white people. I don't know. Some old ladies. We lost her... They didn't come and talk to us. They didn't bring her back so we could see her. But they never bring her back. No. We should be seeing her like, often, and then she go back again, but no, we don't know which carer it is. But we lost her.*

*She is forgetting who I am.*

The family of one boy had not seen him for over a year, since he was placed in foster care. Family members wanted either for the boy to come back on the plane to visit for a day, possibly with his foster carer, or for his immediate family to visit him in the city, 1,500 km away. His grandmother explained:

*We are trying get help to go and sit down and have a holiday with him for two weeks, to visit him... Last time we saw him was in town when he was in hospital... Yes, it was last year.*

When asked where their child was staying and whether they would visit her, this family replied:

*I don't know. I don't know. It is such a long time we have been looking for help. Just talking, you know. Whitefellas, the way they talk, talk, talk. Throw the paper away. Yes, really!*

The cost of travel and accommodation was a major problem for families wanting to visit their children living in the city, as this grandmother explained, *'I really want to see her again, but no money. I can't afford it to go to the city. I want to see my granddaughter. I miss her very much.'* She had been told, *'Get to a regional centre and we might help you'*.

People talked about children with disabilities who had left the Lands many years ago and never been seen or heard of again, as in this instance:

*My sister has got a grandson, but he been sent to - We been sent him a long time - long time, we sent him. We never seen him.*

The woman mentioned above who sent her daughter away for an operation and recuperation on the advice of a doctor, was struggling with pressure from her child's foster carer wanting to keep the child:

*I signed a small paper, which said they would give her back to me when she was two years old, but at two years old, (the foster carer) wanted to keep her for more. Then she became three and then she became four, and then she became five years old, but (the foster carer) wants more, to keep her for more. So I said no.*





Families were insistent about wanting to visit or be visited by their children who had left the Lands to be cared for in regional centres or in the city. However, they felt that the children's high-care needs would prevent them from returning to live on the Lands. This grandmother explained that she wanted to see her granddaughter *'for a visit. Yes, I would like for families to come and visit. No, not to live. Just come and see, families to see'*.

Another grandmother talked about getting help to take some family members to see their sister in foster care, and was asked if the girl could ever come back to live on the Lands. She replied that the girl had *'too much disability'*, and could not come back permanently.

Aṅangu perceived many benefits for children with disabilities who left the Lands for care. Several mentioned the proximity of hospitals as being crucial. There is no hospital on the NPY Lands. When this father was asked if his son should come home for a visit, he said:

*We might get him and the (foster) parents will come down to (the regional centre). And we can sit down there with him. There is a hospital for him. There is a better hospital there. That's why. There are 24-hours doctors.*

#### CONTACT WITH FAMILIES FOR CHILDREN LIVING OFF THE LANDS:

Children with disabilities, particularly those in foster care, often lose contact with their families and culture when living off the Lands.

Most families accept that their children cannot return to the Lands to live because looking after them is 'too hard'.

They grieve for them and want to see and hold them.

A couple of families were able to visit their children.

Most families have difficulty negotiating the system to organise visits to their children and can't afford to travel to regional centres or cities.

### **4.3 Children With Disabilities Living off the Lands with Their Families**

Some families lived in town with their children with disabilities, who were attending schools and receiving services. There were many different arrangements among them. This grandmother of a child with disabilities in town explained:

*Because family decided if you go to stay in town where it is much closer to the hospital... I think it's good for them to stay in town where they can be treated straight away when they get sick, you know?*

One family was spending extended periods in town while they and their son with a hearing and speech impairment learnt sign language, and they returned to the community with the boy between visits. They were extremely happy with the services and support they were receiving, but commented that the time spent living in a regional centre had been difficult for them:



*I still want to go to (that) school. Take him back to that city. Yes, very good... Better to live here. My country. My place. Really hard (in town). Only going for the appointment, for the hearing appointment for him.*

A worker commented on the difficulty for family members in town with their children trying to maintain their ties with the Lands, family and culture:

*There was a funeral back in the community. Somebody died and the parents had to go back. They couldn't not go back. They couldn't take the child with them because the oxygen was all too difficult and the hospital said, 'No, can't. Kid can't go back out even for a few days'. And we had to talk to everyone about the fact that ... If the parents do not go to that funeral, they will be in big trouble because it's their obligation. It's a cultural obligation that they go. And it brought up all these problems around, 'Well, how do we...? The child needs respite', and it got very difficult... He was being left at the hospital. But then ... there was a set respite every two months, I think, of four days, five days ...*

A woman who had returned to visit community for a funeral talked about her grandson with severe behavioural problems:

*Welfare didn't get him at that point because I shifted him to the city to put him into a good and appropriate school. ... He is playing football now. All the children there are learning really slowly and carefully how to speak properly. If there is any incidence of teasing, the teachers step in straight away and help him. He is given really good help with getting to football. He gets picked up and brought back... Yes. I will stay in the city. There is good help down there. There are lots of good things.*

In the city, she was receiving good support to look after her grandson, such as organising uniforms, arranging buses, domestic help and so on. However, a family who moved to a regional centre because of their teenage son's needs, and lived in a town camp while waiting for housing, found that, despite the increased availability of support services, the overall effects of living in town were negative. A worker said the boy was 'getting caught up in a lot of stuff in town that you're not exposed to in community', and the family returned to the community with him in order to keep him away from those influences.

The logistics of finding accommodation, living without family support and culture, and supporting a child through the disability and health care systems in town are too complex for many people from the Lands. Workers commented on some of the options for accommodation for families supporting their children with disabilities:

*I think there are a few kids where there's a shared-care arrangement, where they might be living in town but they're not under departmental control or anything like that. There's kind of a different sort of arrangement and, unfortunately, I think that that might become more problematic once NDIS hits.*

*And we're at the stage now with some of those that, because they're voluntarily in town, funded by us to be in 24/7 supported accommodation, we understand that the NDIS won't, they won't pay for that to happen ... Because the children are under the care of the Minister... so either they go back ... Well, we don't know what's going to happen. We have to sort this out ... the children would be at risk if they go back out. Some of them would be anyway.*



However, an education worker pointed out that the number of families staying in town with their children was increasing:

*When I started, I think 90% of our Aboriginal kids lived in supported accommodation. That's down to about 60 (%) now because of the children who live with their families.*

There are many issues for people in this situation, including finding satisfactory and affordable accommodation, supporting their child and any other children who may be with them and, crucially, maintaining ties with family, culture and the Lands. This is not an easy decision for people to make and is an ongoing issue for those families.

**FAMILIES LIVING OFF THE LANDS WITH THEIR CHILDREN WITH DISABILITIES:**

Some families move into town to support their children who need access to care support, specialist facilities or special education.

Families need support with such things as accommodation and negotiating the health and disability systems.

Because they are away from their homes and extended families, they need support to return to the Lands for cultural events, such as funerals, with or without the children they care for.

#### **4.4 The Future for Children with Disabilities Living off the Lands**

Families on the Lands were troubled about the future of the children who had moved away from the Lands and expressed their worries:

*It does make us feel sad, you know... families... what might happen to him in the future, you know, as he is growing a bit older.*

*They think he is getting old. Last time he got sick, you know, in his chest. They told me that he has to go to hospital when he gets really sick. And he has to stay there by himself, poor thing.*





## 5 THE FINDINGS: IMPLICATIONS

### 5.1 Meeting the Project Aims

The aim of the Tjitji Aṭunymankupai Walytja Tjuṭangku project was to identify the supports and mechanisms required for Aṅangu families (the main care providers) of children with disabilities from remote and very remote NPY communities, in order for them to live the lives that they desire. A further project aim was to identify, from the perspective of Aboriginal families and service providers, the factors that influence these families to stay in or leave their communities. It was also intended that the project findings should suggest culturally responsive supports for families of children with disabilities on the Lands.

The project findings, in relation to families living on the Lands with children with disabilities, were clear, leading to recommendations for culturally responsive supports for those families on the Lands as discussed below. Several families who had moved off the Lands to support their children were also interviewed. However, as detailed in section 4, this project identified that many children with high-care needs had moved away from their families and the Lands because their care or medical support needs were unable to be met. Families felt the loss of these children deeply and found it hard to maintain contact with them. Recommendations arising from these findings relate to keeping children with disabilities on the Lands, and when this is not possible, enabling their family members to maintain relationships with them.

There are several NDIS-related issues raised in this report regarding children with disabilities from the NPY Lands. Due to the remote geographic location, isolation, small population base and limited infrastructure in the communities on the NPY Lands, providers need support to take their services to communities. This support will not be achieved with the current NDIS market-based model. In order to provide services, particularly culturally responsive services, where people can work with Aṅangu in a respectful, responsive and trusting way, alternative methods of supporting service organisations to have a presence in the Lands need to be considered. Block funding would allow services to be made available in remote communities to provide support for children and families. Block funding services would also provide security for organisations and staff, enabling them to work in a culturally appropriate manner, and to build relationships with families to develop an understanding of each situation and respond to their needs.

### 5.2 Keeping Children on the Lands

Aṅangu families tried hard to keep their children with disabilities with them on the Lands. Some families were eventually forced to acknowledge that their children could not be adequately supported in remote communities and needed to leave their homes to live in larger centres. These families grieved for the loss of their children and the lack of contact with them.

In order to keep as many children with disabilities as possible living on the Lands with their families, and receiving appropriate care, families need substantially more support than has previously been available in remote communities. Children with disabilities need support in ways that build their social and emotional wellbeing, as well as look after their physical needs. Family wellbeing is crucial for keeping children on the Lands with their families and culture. This is especially so for those families looking after a child with high-care needs. Care for children with high needs can be additionally problematic in remote communities because many care techniques and processes do not align with the traditional Aṅangu culture.



### **5.2.1 Basic Needs**

As a starting point, families require help with everyday, basic needs to ensure that they have access to adequate food, clothing and bedding. Not having these items means that they will always be focussed on obtaining them for their children and themselves, and they will not look at longer-term issues, such as those related to their children's disabilities. Access to basic needs is a crucial and fundamental step in order to keep children with disabilities on the Lands, and funding is required to ensure this. The NDIS needs to consider ways to support families who are caring for children with disabilities as an integral part of supporting the children with disabilities themselves. This is likely to include the provision of periodic access to some of the basic necessities of life: food, clothing and bedding.

### **5.2.2 Day-to-day Care Assistance for Families**

Many Anangu with children who have a disability need extra help, particularly if their child has high-care needs. Workers suggested that several hours of in-home assistance per day might alleviate some stress on families. Currently, there are minimal services on the Lands providing this sort of help. Some families were reluctant to have workers in their homes, particularly people they did not know and trust, so this type of assistance would involve the development of a flexible working model to provide care assistance while accommodating people's cultural and personal sensitivities. However, NDIS approval of such services does not mean that the services will become available. Organisations require additional targeted block funding to maintain an adequate number of workers to take up this role in remote communities.

Another area where Anangu families of children with disabilities need support is in relation to understanding the nature of the relevant disability and the implications and possible benefits of medical interventions, care techniques and therapy. This case management and/or advocacy support could be given by a worker living on the Lands, who builds relationships with families and works across a number of communities. Because of the complex issues faced by families and service providers, families may also need ongoing case management centred on children with disabilities. NDIS funding might be used to cover these services, either on a service-by-service basis or through block funding.

### **5.2.3 Culturally Responsive Workers**

People who are working closely with affected families must be culturally aware and have cultural orientation and ongoing mentoring, led by Anangu. The NDIS pricing needs to take this into account, or else funding should be provided separately for cultural orientation and mentoring of service providers. The model for working on the Lands must enable workers to spend time with families to build the trusting relationships that are vital for Anangu to engage with services. Minimising staff turnover wherever possible is crucial, as is responding to worker concerns and supporting them in their life in the community.

Because Anangu families are often reluctant to engage with people they do not know and trust, the NDIA needs to employ people, either based on the Lands or spending a considerable amount of time there, to work with families around engaging with NDIS services and to develop plans for those services. An alternative would be to work through an established and accepted organisation whose workers have already built trusting relationships with Anangu and are able to develop an understanding of the situation of families looking after children with disabilities.

### **5.2.4 Local Workforce Development**

In the longer term, the development of a local disability support workforce will help to fill the need for day-to-day support of families looking after children with disabilities. Anangu interested in these positions require support and supervision in order to join and remain in the workforce. Such a



workforce will require the development of a flexible working model that responds appropriately to community interactions and people's cultural commitments. This is an area where the NDIA could work with State or Territory Governments to ensure ongoing support and supervision for an Aboriginal workforce within an appropriate cultural model of employment.

### **5.2.5 Access to Specialist Services on the Lands**

Specialist workers, such as paediatricians and allied health workers, currently visit the Lands irregularly, and many stay for short, time-limited periods. To overcome this challenge, services need to be based on the Lands, or at least funded for more frequent and longer visits to the communities there. This approach would provide better support for people and offer the chance for Anangu to develop more trusting relationships with specialists. Alternative models of service might involve working with a person already living on the Lands who would have the opportunity to get to know the families concerned, or working alongside an established and trusted organisation. The worker on the ground would be able to explain the purpose and benefits of each specialist and provide advocacy support for the families. Either of these possibilities might require some restructuring of the NDIS pricing strategy.

### **5.2.6 Schools**

Many families suggested that schools require additional resources for specialist workers and extra classroom support for children with disabilities. One possibility would be to develop Aboriginal education worker roles to fill some of these functions. This would involve training people to work with children with specific disabilities and providing ongoing support and supervision. Currently, funding Aboriginal education staff is the responsibility of State and Territory education departments and, in order to maximise the benefit to students with disabilities, a more flexible approach might involve using a child's NDIS funding for the provision of support to a specific child with a disability. Because of the number of child therapists and specialists who work through the schools in the NPY Lands, there is scope for the NDIS to work with the education departments to streamline this process.

### **5.2.7 Respite**

Respite was one of the common requests from family members looking after children with disabilities. Family members need respite so that they can continue to provide care for their child. Some carers have good family support and can call on other members of their family to care for the child with a disability while they take a break. However, many don't have this resource and need external support to be able to take a break from the care routine - either with day activities in the community or a longer break in town away from the Lands.

Opportunities for in-community respite are almost non-existent on the Lands. The provision of regular opportunities for a break requires specific funding focussed on maintaining carers' health and wellbeing so they can continue to care for the child with disabilities in their families. With the rollout of the NDIS, respite may form part of a participant's plan, but there is no provision for respite for family members caring for a child with a disability, despite the importance of maintaining people in this role.

### **5.2.8 Flexibility of Support**

On the NPY Lands, the principal person looking after a child may not be a parent, but another family member. Grandparents, aunts and uncles often fill this role, and services must take this into account. Care might not be provided consistently by one person, as it is culturally acceptable for children to be looked after by different family members at different times. Organisations providing funding (such as the NDIA and Centrelink) need to make allowances for this flexibility so that they can respond in an appropriate and supportive way to such situations.



### **5.2.9 Disability Accommodation on the Lands**

One of the participants suggested there should be supported accommodation on the Lands to enable some children who are living away from the Lands to return and be cared for close to their families and homes. It would also enable children unable to return long-term at least to visit the NPY Lands, along with their carers or fostering adults. Children who live off the Lands due to their high care needs could possibly spend time with their families at such a facility, giving them contact with family as well as increased understanding of their background and culture. This proposal could also provide an option for respite for families who are looking after children with disabilities on the Lands.

## **5.3 Children with Disabilities Living off the Lands**

Many children living off the Lands lose contact with their families, homes and culture. There are some issues with regard to families retaining their parental rights when their children leave the Lands for services and care support. It should be possible for families to surrender their children because of being unable to provide adequate care for the child, without losing their parental rights or being deprived of contact. Children with disabilities from the NPY Lands need contact with their families, homes and culture.

### **5.3.1 Children with Disabilities in Supported Accommodation**

Several children in supported accommodation did have contact with their families and one service provider mentioned that two children visited their homes on the Lands, one in particular returning home regularly in the school holidays. Other children had varying levels of family contact, from occasional family visits to no knowledge of their family of origin.

Service providers emphasised the hard life for children who either have no known family and/or who bounce between foster carers and supported accommodation. For these children, it is imperative that the workers who look after them are encouraged to stay with them long enough to develop relationships and to fill the role of caring adult. Those workers would need to undertake cultural orientation and training guided by Anangu. This may involve revising the conditions of employment for carers and workers in these organisations, and possibly higher funding levels for the organisations. Children with disabilities in supported accommodation need to visit their home communities regularly, accompanied and supported by paid carers. Funding for such visits should be automatically available to them.

### **5.3.2 Children with Disabilities in Foster Care**

Families who have given children with disabilities up to foster care need support to maintain a relationship with their children. Advocacy and case management workers should be available to provide assistance to make this happen, working with Anangu and with the service organisations involved in the fostering process. Anangu want to see and touch their children, not just to receive reports or birthday video links. Because the costs of remote travel are high, many people may also require financial assistance in order to arrange visits with their children.

### **5.3.3 Families in Town Who Have Children with Disabilities**

Families who have left the Lands to support children with disabilities need help and advice around such things as accommodation, how to find services to help with the care of their children, budgeting and negotiating the disability and health care systems.

There is also a need for 'reverse respite' systems, so these families can return to the Lands from time to time, leaving their children in caring hands for short periods, if the children are unable to accompany them. The wellbeing of Anangu is dependent on being able to return to their families, homes and culture from time to time. It is necessary in order to maintain people's emotional, mental and physical health and, in turn, the ability to look after their children as well as possible.







## 6 RECOMMENDATIONS

### 6.1 For Children With Disabilities Living on the Lands

#### 6.1.1 Families Need Support to Care for Children with Disabilities on the Lands

Families of children with disabilities from the NPY Lands want to keep their children with them on the Lands and need support to do so, which includes the following:

- assistance with basic needs - food, bedding, clothing;
- in-home, day-to-day care support, particularly for children with high support and care needs, delivered through culturally appropriate and flexible working models that respond to people's sensitivities;
- access to therapeutic and specialist services, including diagnostics, physiotherapy, occupational therapy, speech therapy, paediatrics, psychiatrists, hearing specialists and dietitians;
- access to appropriate allied health equipment and housing modifications;
- advice and advocacy support regarding the nature of disability, therapy and care assistance, delivered in a culturally appropriate manner;
- access to ongoing case management centred around the child with a disability for families faced with complex issues of care support and access to services;
- flexible and culturally appropriate respite opportunities - both in the community and away from the community.

#### 6.1.2 Service Providers on the Lands

Service provider organisations for children with disabilities on the Lands:

- need to be Lands-based or able to utilise the services of a person or organisation that is Lands-based in order to
  - ensure a culturally acceptable way of working, and to
  - develop relationships with families of children with disabilities on the Lands;
- if visiting the Lands, rather than being Lands-based, services need to plan sufficient time in each community to locate people and spend quality time with them, as opposed to visiting, consulting briefly, and then leaving.

Schools on the Lands need sufficient resources to support children with disabilities through:

- increased specialist visits (e.g. speech therapists, physiotherapists, occupational therapists, paediatricians);
- resources to allow for closer interaction with visiting specialists who are not part of the education system;



- more in-class support for children with disabilities, possibly through building the Aboriginal education officer workforce.

### **6.1.3 Culturally Appropriate Ways of Working**

All non-Aboriginal workers on the Lands (including specialists) need:

- cultural orientation and ongoing mentoring, guided by Anangu;
- to work in a culturally responsive manner;
  - building relationships with Anangu that are based on trust and understanding;
  - listening and responding to what people want;
- to recognise and work with Aboriginal cultural differences from mainstream society, including family relationships and responsibilities for bringing up children;
- adequate funding to enable them to work proactively with families and to develop trusting relationships with those families in order to encourage engagement with appropriate services.

The development of a local workforce is one long-term solution to the challenges of high staff turnover to ensure cultural appropriateness. Such a workforce will require:

- ongoing training and support;
- a flexible working model to accommodate cultural requirements.

### **6.1.4 Supported Accommodation on the NPY Lands for Children with Disabilities**

The establishment of supported disability accommodation on the Lands with ongoing funding for staffing and maintenance would respond effectively to a number of the issues raised in this report by providing:

- assistance to families caring for children with disabilities on the Lands through advice and guidance;
- occasional respite for families; a base for children living in town to visit the Lands;
- the possibility of accommodation on the Lands for children with disabilities whose care needs are too high for families to look after them.

## **6.2 For Children with Disabilities Who Live off the Lands**

### **6.2.1 Families in Community of Children with Disabilities Living off the Lands**

Families living on the Lands whose children with disabilities are living off the Lands need support to maintain a relationship with their children, including:



- a case manager and advocate on the Lands who can help them negotiate the systems around visits to or from their children;
- financial support for visits to and from their children;
- if they are unable to care for a child, the ability to surrender their child without losing their parental rights, contact and rights of access.

The establishment of supported accommodation on the Lands for children with disabilities would facilitate visits to the Lands and access to families and culture.

### **6.2.2 Children with Disabilities in Supported Accommodation**

For children living in supported accommodation in regional centres or cities, away from their families:

- accommodation organisations need to focus on hiring care workers who are likely to stay long term;
- workers and management of accommodation organisations should be given cultural orientation guided by Anangu;
- ‘reverse respite’ visits need to be included in funding packages to enable children to return home and have regular contact with their families, the Lands and culture.

### **6.2.3 Families in Town Who Have Children with Disabilities**

Families who have moved away from the Lands because of the needs of children with disabilities require support, including:

- a case manager and advocate who will help with the logistics of living in town or in a city with a child with disability and be a primary point of contact for families;
- the option of having the child in respite from time to time so the family can return to the Lands in order to maintain their emotional wellbeing and to fulfil cultural obligations.



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The project research team. From left to right: Dr John Gilroy, Ms Heather Jensen, Ms Kim McRae, Ms Lee Ryall, Mrs Margaret Smith, Dr Rebecca Barton, Associate Professor Kerry Taylor, Professor Vicki Flood, Dr Angela Dew, Professor Michelle Lincoln.



## References

1. Information and Evaluation Branch, Department of the Prime Minister and Cabinet: NPY Lands Empowered Communities Region Regional Profile – Outcomes for Indigenous Australians.
2. <https://www.aihw.gov.au/getmedia/3a8073e1-3a91-49a3-8f8a-fd376aceea15/AW15-3-8-Wellbeing-of-Indigenous-children.pdf.aspx> Accessed 1 February, 2019.
3. <http://www.abs.gov.au/ausstats%5Cabs@nsf/0/176B7899CCE3B173CA257D9E00112463?Opendocument> Accessed 1 February, 2019.
4. Gilroy, J., Lincoln, M., Taylor, K., Flood, V., Dew, A., Jensen, H., Barton, R., Ryall, L., and McRae, K. Walykumunu Nyinaratjaku: To live a good life. 2018, Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation: Alice Springs, Northern Territory.
5. Ngaanyatjarra, Pitjantjatjara, Yankunytjatjara Women's Council & Woenne-Green, Susan & Australian Aged and Community Care Division (1995). They Might have to Drag me Like a Bullock: the Tjilpi Pampa Tjutaku Project: the rights, needs and care options of the senior men and women of the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara communities in the cross-border region of Central Australia: final report March 1995. Alice Springs, Northern Territory. Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation.
6. <https://education.nt.gov.au/education/support-for-teachers/faft> Accessed 1 February, 2019.
7. <http://www.supportingcarers.snaicc.org.au/caring-for-kids/child-rearing-practices/> Bonding and attachment of Australian Aboriginal children. CFCA Paper No. 25. Published by the Australian Institute of Family Studies, September, 2014. Accessed 1 February, 2019.
8. Priest, K., King, S., Nangala, I., Brown, W., and Nangala, M. (2008). 'Warrki Jarrinjaku working together everyone and listening: Growing together as leaders for Aboriginal children in remote central Australia. European Early Childhood Education Research Journal, Vol. 16, No. 1, 117–130.
9. Secretariat of National Aboriginal and Islander Child Care. 2012, Growing up our way: Aboriginal and Torres Strait Islander child rearing practices matrix. Secretariat of National Aboriginal and Torres Strait Islander Child Care, North Fitzroy, Vic. <https://www.snaicc.org.au/growing-up-our-way-aboriginal-and-torres-strait-islander-child-rearing-practices-matrix-2011-snaicc/> Accessed March 13 2019.



## Trigger Questions Used in Interviews with Anangu Families

1. These trigger questions act as reminder points for the interviewer of what needs to be covered. The interview should be a conversation and hopefully will elicit additional detail enabling the interviewer to follow up points of interest.
2. Has your child lived in this community for a long time?  
Sometimes the child may live elsewhere
3. When did you and your child come here? Why did you come here?
4. Where do you usually live? Is that where you want to live?
5. Do you or your child live in other communities?
6. Who else lives in this house with you?
7. Who looks after your child when you go away?
8. Where does the rest of your family live?
9. What do you or your child like to do...football, visit town, go hunting...?
10. What do you and your child do most days? .... Go to school, sit and talk, go hunting....  
Does your child go to school sometimes/most days/a lot?
11. Are there things that you or your child want to do but can't?  
Why can't you do these things?
12. What do you worry about?
13. What would make your life better? What would make your child's life better?
14. Who helps you and your child? E.g., family, clinic, workers. Are these the people you want helping you? What makes a good worker?
15. What kind of help do you need? Give participant the opportunity to respond and, if needed, be prepared to suggest examples, as follows. Be really clear that you are not making promises.  
Assistive equipment, as appropriate (wheelchair, wheelie walker, toilet chairs, bedding).  
Help with tasks, such as transport, housework, shopping, etc.  
A break from looking after your child.  
More cultural and social activities (hunting, artwork, business, football, sorry camps...).  
Living somewhere else (Alice Springs/Adelaide/Port Augusta).  
Repairs to housing- rails/ramps.





## Trigger Questions Used in Interviews with Service Providers Who Work with Children with Disabilities from the NPY Lands

1. Can you tell me about the organisation you work for and explain your role, experience and how you work (in community/in town)?
2. How do Anangu with disabilities connect with your service? Which services do Anangu families who have a child with a disability access in this organisation?
3. Do you engage with communities in the NPY region?
4. What are the main supports for families who have children with disabilities at home and in the community?
5. If you can, give me an example of an Anangu child with a disability successfully supported to live a life that they choose? Is this person's experience unique or common?
  - 5.1. Does this involve overcoming any barriers?
  - 5.2. What are the main support structures in the home and community?
  - 5.3. Who in the community provides the main support/care?
6. If you can, give me an example of an Anangu child with a disability who is not successfully supported to live the life that they choose? Is this person's experience unique or common?
  - 6.1. What are the barriers that prevent this person from living the life they desire?  
If so, can you explain them?
  - 6.2. Are there mechanisms that could be put in place to help that person to live the life they choose?
7. In your experience, what factors are essential to enable Anangu children with a disability to live the life they choose?
  - 7.1. What roles do non-disability service providers play in enabling Anangu with a disability to live the life they choose?
8. Are specialist/mainstream services/programs needed in the communities to enable Anangu children with disabilities to live the life that they choose? If so, what types of specialist services? How would these services enable Anangu with a disability to live the life they choose?
9. In your experience, what factors are essential for establishing clear pathways for Anangu families who have children with disabilities to access your community services/programs?
10. Are systems getting in the way of delivering a service that enables Anangu families who have children with disabilities to live the life they choose?



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