



# Walykumunu Nyinaratjaku



*To live a good life*





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*To live a good life*



Ngaanyatjarra  
Pitjantjatjara  
Yankunytjatjara  
Women's Council  
(Aboriginal Corporation)



THE UNIVERSITY OF  
SYDNEY





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Aboriginal Corporation

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Cover Painting and design above by Margaret Smith, Imanpa 2017



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.



This project is to help the people of the Lands. Especially the people with disabilities. Their needs – they really do need to have them met. You just can't make new rules and just go and tell the Aṅangu that this is what we're going to do and this is how we're going to go about it.

The first thing you've got to do is to ask the Aṅangu, the people, whether she or he has an opinion to say what's best for her, what she thinks or he thinks. It's got to suit her on the Lands.

To get a good outcome, work side by side with the Sydney Uni and the NPY Women's Council directors and the staff.

Margaret Smith  
Director, NPY Women's Council  
Imanpa, 2016



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## Executive summary

### Background

*Walykumunu nyinaratjaku* means 'To live a good life' in the Ngaanyatjarra language. This research project was initiated by the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (NPYWC). The project asked the question, 'What makes a good life for Aboriginal people with a disability from the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara (NPY) Lands?'. Anangu and Yarnangu with disabilities and the family members who are, with few exceptions, their principal carers were interviewed, as were workers from organisations that support Anangu and Yarnangu. The report summarises those discussions, looks at the factors that enable or impede the achievement of that good life, and makes recommendations for providing culturally appropriate services.

### Findings

The most significant finding of this research is that Anangu and Yarnangu with a disability want to live in their communities, on the NPY lands, with family. This is more important to them than the quality of care they receive, or the availability of services. It is important despite the difficulties they encounter in accessing basic daily amenities including food, clothing and bedding, which remain a major priority for people living in community.

For those Anangu and Yarnangu with a disability who *are* living in community, a good life also means being included and participating in cultural, family and community activities such as arts and crafts, bush trips, bush medicine, music, television and movies, sport, socialising, spiritual life and shopping.

### Recommendations

The principal findings and the recommendations from this report have been incorporated into a three-part conceptual framework: *Heart* (emotions), *Head* (knowledge), and *Hands* (actions).

This framework, derived from work by Rippon and Hopkins, was suggested by the information we gathered, and is useful for all agencies that provide services on the NPY Lands. The three elements of the framework overlap and are interrelated, so each recommendation is listed here under the most relevant element.

### *Heart*

Anangu and Yarnangu with disabilities want to stay on country with family and culture, taking part in meaningful activities and interacting with family members and trusted service providers. Anangu and Yarnangu with a disability who are living away from the NPY Lands want to return to the Lands. With few exceptions, all of the care for Anangu and Yarnangu with disabilities on the NPY Lands is provided by family. Therefore the welfare of family carers is essential to enabling Anangu and Yarnangu with disabilities to remain on the Lands.



- Family carers need support in a range of ways, including:
  - a flexible respite model that provides a break when needed, either on or off the Lands
  - assistance with caring for the person with disability
  - domestic and laundry assistance.
- People with disability need supports aimed at enabling them to participate in cultural, family and community activities, including appropriate equipment and transport.
- Anangu and Yarnangu with a disability who are living away from the NPY Lands need to return regularly to the Lands, whether through more flexible respite options or other specific programs.
- Long-term, consistent services are needed to enable Anangu and Yarnangu who have disabilities to build trusting and respectful relationships with workers.

### **Head**

All interactions between Anangu and Yarnangu with disability, their carers, service providers and policy makers should be based on internationally recognised human rights and responsibilities. Regardless of geographic location, all people with disability should be able to obtain culturally appropriate support and the services they need to live a good life.

Policy makers and service providers should acknowledge and respond to the particular strengths, circumstances and difficulties faced by Anangu and Yarnangu with a disability living on the NPY Lands, in all policy relating to those areas.

- Anangu and Yarnangu with a disability need flexible services that are responsive and culturally appropriate.
- Anangu and Yarnangu need to guide policies and practices for disability support on the NPY Lands. To achieve this:
  - Policy development needs to begin with listening to Anangu and Yarnangu. Policy makers should also continue to seek regular feedback.
  - Organisations working with people in remote communities need to involve Anangu and Yarnangu in all levels of their operation, from board members to workers, to ensure appropriate cultural guidance and feedback.
- Anangu and Yarnangu and service providers need to work together to better understand each other's expectations of the carer role.
- Policy makers and service providers need to develop and implement strategies to ensure quality orientation, cultural training and support for disability staff working with people on, or from, the Lands.
  - Continuing cultural responsiveness needs to be facilitated through mentoring by Anangu and Yarnangu.
- Policy makers and service providers always need to use interpreters when working with Anangu and Yarnangu.
- Policy makers and service providers need to work with Anangu and Yarnangu to develop



a common understanding of appropriate roles for a local workforce to assist people who have a disability.

- These need to consider a wide range of roles, including carer support and equipment maintenance.
- Organisations need to take a long-term approach to developing the workforce, both Aboriginal and non-Aboriginal, that recognises and provides appropriate levels of engagement, education and support.
- There needs to be flexibility in the processes, management and costing of the National Disability Insurance Agency (NDIA) to respond to the particular difficulties faced by people with a disability living on the NPY Lands.
  - Representatives of the NDIA need to consult regularly with Anangu and Yarnangu to ensure all people with a disability receive the full benefits of the National Disability Insurance Scheme (NDIS).

### **Hands**

The first priority for Anangu and Yarnangu with disability and their carers is to obtain basic necessities. They also want to take part in culturally appropriate, meaningful community activities. Support for these requirements and activities needs to be provided by a caring, skilled, culturally responsive and well-resourced workforce that includes both Aboriginal and non-Aboriginal workers.

- Anangu and Yarnangu need help with basic goods and services, including:
  - meals
  - bedding, clothing and basic household goods
  - domestic assistance
  - equipment and supports such as basic therapeutic assistance, assistance with activities of daily living, transport, and life-skills training.
- Anangu and Yarnangu are entitled to and need equal access to services, including:
  - allied health services, equipment and support
  - diagnosis of and support for cognitive and neurological disorders
  - mental health services
  - drug and substance-misuse services
  - carer support services.
- Community infrastructure needs development so that workers can stay on the Lands for extended periods of time and develop the trusting relationships that are crucial in working with Anangu and Yarnangu with a disability.

The responsible agencies need to ensure that all new buildings on NPY Lands meet universal housing standards, so they are accessible for Anangu and Yarnangu with disabilities.





## 1. Introduction

This is the final report for the collaborative research project *Walykumunu Nyinaratjaku: To Live a Good Life*, which examined what makes a good life for Aboriginal people with a disability from the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara (NPY) Lands.

Nationally, the estimated rates of disability for Aboriginal people are at least twice as high as the rates for the general Australian population.

Aṅangu and Yarnangu (Aboriginal people) from the NPY Lands were asked to share their experiences, opinions and perspectives on what constitutes a good life for people with disabilities. The findings from this research project provide a framework for providing culturally responsive supports to enable people with disabilities to live a good life as defined by Aṅangu and Yarnangu.

### 1.1. Background: Remote communities of the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara (NPY) Lands

The Aṅangu and Yarnangu of the NPY Lands in the Central Australian cross-border region are closely connected to their traditional culture, family and country. They speak as their first language one or more of the ancient local languages, Ngaanyatjarra, Ngaatjatjara, Pitjantjatjara or Yankunytjatjara. The arrival of European culture and the change from a nomadic to a more settled lifestyle is within living memory.

The NPY Lands consist of 25 very remote communities and homelands, spread across 350,000 square kilometres of semi-arid country. As shown in Figure 1, the region is made up of the Shire of Ngaanyatjarraku in Western Australia, the four southernmost communities of the Northern Territory, and the Aṅangu Pitjantjatjara Yankunytjatjara (APY) Lands in the north of South Australia. The communities are geographically remote, and almost all are reached by unsealed roads, which are subject to closures for cultural activities and wet weather.

The total population of the region is around 6000, and numbers in individual communities range from fewer than 100 residents, up to 585, with an average of around 200. All communities have limited access to goods and services, typically being served by a single store, a clinic, a school, and a community office. Regional service centres are located in Alice Springs (Northern Territory), Kalgoorlie (Western Australia), and Port Augusta (South Australia), at distances of between 300 and 1500 kilometres from communities.



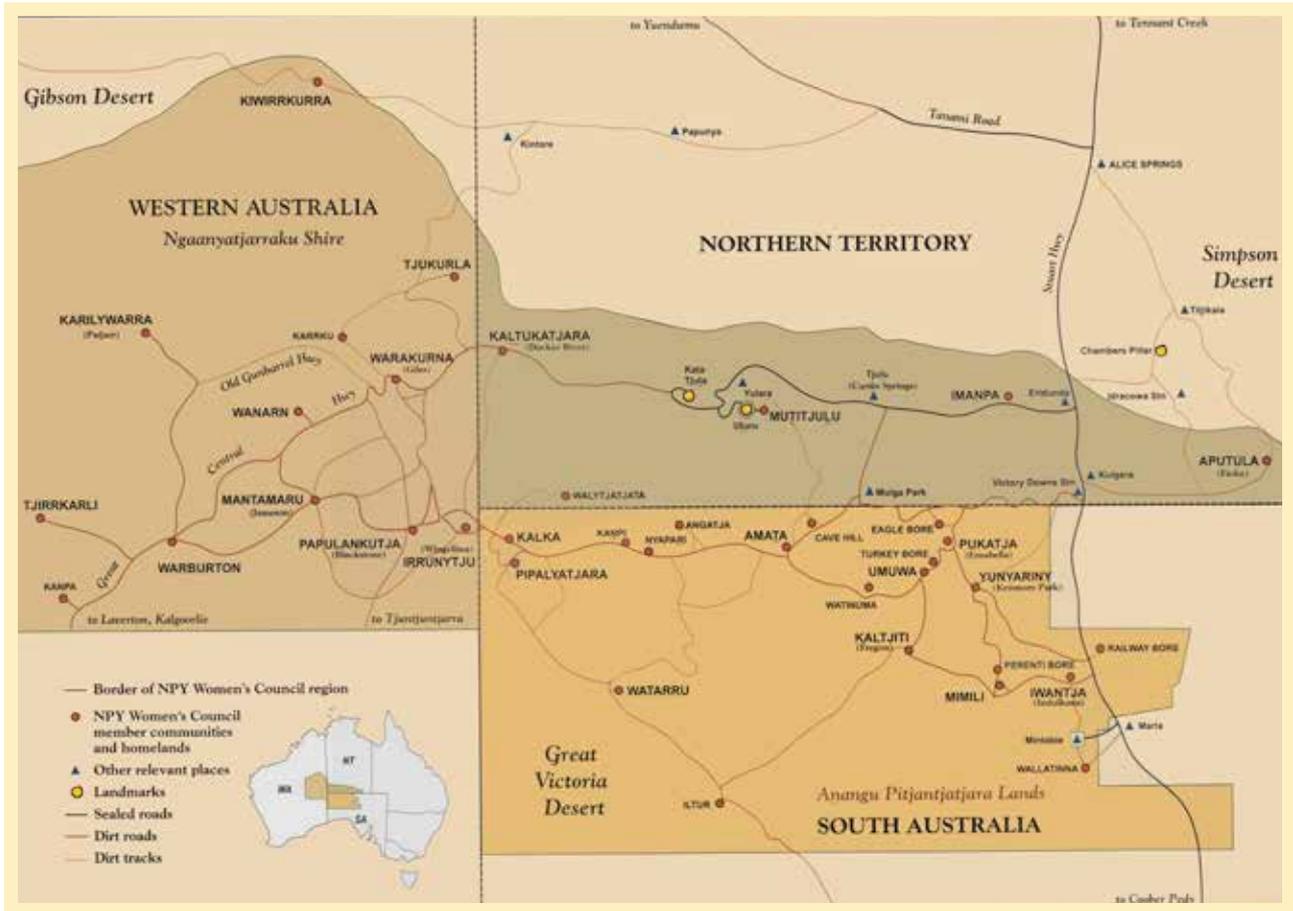


Figure 1: Map of the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands, Central Australia.

## 1.2. The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council (Aboriginal Corporation)

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council (NPYWC) was established as an advocacy organisation in 1980 by Aboriginal women from the NPY Lands. Since then, the NPYWC’s role has expanded to include a growing range of human services that increase the capacity of women and their families to lead safe and healthy lives and to have better life choices.

In 1993 the Tjungu team was formed, to provide services to Anangu and Yarnangu who are aged and/or have a disability, and their carers. The team gives people living on the Lands practical help, as well as offering advocacy and a range of referrals.

*Nganana alatji nyinanyi – wiru way, piranpa munu maru tjungu – nganampa tjukurpa. (This is how we work – white people and black people working together – it is a good way and it is our culture.*

Senior woman from the APY Lands, one of the founders of the Tjungu team, July 2007.



## 2. The Walykumunu Nyinaratjaku research project

### 2.1. Walykumunu nyinaratjaku: to live a good life

#### WHAT WAS THE PROJECT ABOUT?

What do Anangu and Yarnangu with disabilities from the NPY Lands need in order to live a good life?

In 1994–95, NPYWC researched and published a report, *They might have to drag me like a bullock*, on the situation of older Aboriginal people on the NPY Lands. In the report, older Anangu and Yarnangu expressed their determination to stay on the Lands to the end.

How Anangu and Yarnangu with disabilities perceive a good life and want to live their lives has never before been documented. Without this information, services cannot be responsive to the aspirations of Anangu and Yarnangu. Instead, service providers and funders provide the services they think people require. This project, undertaken at a time when disability funding and services are changing with the establishment of the National Disability Insurance Scheme (NDIS), fills the gap between the aspirations of Anangu and Yarnangu on the one hand, and the perceptions of service providers and funders on the other. The project also looked at factors that help people in achieving their desired way of life – or hinder them. A further project, funded by an Australian Research Council Discovery Indigenous Grant, talks to families of children with disabilities about their specific situation, and will be reported elsewhere.

NPYWC identified the necessity of documenting the desires and needs of Anangu and Yarnangu with disabilities and their carers, and approached the research partners to join them in this project. Walykumunu Nyinaratjaku (To Live a Good Life) is a collaboration between 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 was funded by the Australian Government Research and Data Working Group and began in early 2015. The directors of NPYWC oversaw the project, providing governance and guidance. Approval was obtained from State and Territory ethics committees. Interviews were held between July 2016 and Sept 2017 with two groups of people:

- Anangu and Yarnangu from the NPY Lands, who were over 18 years of age and have a disability or who care for an adult with a disability.
- Service providers supporting Anangu and Yarnangu with disabilities, whether on or off the NPY Lands.



## 2.2 Participants

### WHO WAS INVOLVED IN THE PROJECT?

55 Anangu and Yarnangu  
living on the NPY Lands, all over 18 years of age,  
who have a disability or who care for an adult with a disability.

7 Anangu and Yarnangu  
with a disability, living off the NPY Lands.

47 workers  
from 16 agencies supporting Anangu and  
Yarnangu with disabilities.

### 2.2.1 Anangu and Yarnangu

We interviewed 55 Anangu and Yarnangu living in 11 communities across the NPY Lands. Of these participants, 27 were adults with a disability, and 28 were people caring for adults with a disability. The interviewer was chosen by the NPYWC directors, and where appropriate she worked with a *malpa* (an Indigenous co-worker). Interviews were conducted in the local language, English, or a mixture of the two, depending on the preference of the person being interviewed. Participants' responses were wide ranging and varied. Interviews in Aboriginal languages were subsequently translated into English.

People interviewed on the NPY Lands were aged between 23 and 86 years. People with a disability were evenly split between male and female. In contrast, the carers were overwhelmingly female, and tended to be older than the family member they were caring for.

In addition, interviews were held with seven people (three men and four women) aged between 26 and 63 years, living in supported accommodation in regional centres. Many people with a disability living off the Lands do so as a result of severe acquired brain injury, and this limited the number of possible interviews with people living off the Lands.





Table 1 Disability type reported by Anangu and Yarnangu participants<sup>1,2</sup>

Primary disability type	Number of people
Acquired brain injury	18
Intellectual disability	7
Mobility	5
Cerebral palsy	4
Other physical	2
Hearing	2
Amputee	1
Paraplegia or quadriplegia	1
Parkinson's	1
Psychological	1
Vision	1
<b>TOTAL</b>	<b>43</b>

### 2.2.2. Service providers

Interviews were also conducted with 47 participants employed by 16 service provider agencies working with Anangu and Yarnangu who have disabilities (11 non-government organisations, four government agencies and one private specialist). The agencies provide services on the NPY Lands or in regional centres, or both.

These organisations support Anangu and Yarnangu who have a disability with services including advocacy, accommodation, respite, case management, supported employment, guardianship, primary health, mental health, allied health, personal care support, and financial support.

The 47 participants were employed as direct support workers, case workers, managers, allied health professionals, advocates, and guardians. All but one were non-Aboriginal.

### 2.3. Data analysis

**WHAT DID WE DO?**

We listened to what Anangu and Yarnangu and service providers told us about living with a disability on the NPY Lands. We took everyone's experiences and ideas and looked for things that were common or reported by lots of people.

<sup>1</sup> These numbers comprise 'participants with a disability' and 'people with a disability cared for by participants without a disability'. Some participants with a disability were interviewed with their carer, and carers were occasionally interviewed in a family group, so there were more carer participants than people with disabilities.

<sup>2</sup> These figures include the seven people living off the Lands.



All interviews were recorded, translated and transcribed. They were then analysed by research team members.<sup>3</sup> Following initial analysis, a group of malpa clarified and verified the findings. Analysis identified the common elements and strongly held views expressed in the responses. These defined the most important elements of a good life for people with disabilities and their carers in remote Central Australian communities.

After completing this analysis, we developed concepts and recommendations for delivering appropriate and culturally responsive services that will enable Anangu and Yarnangu to live a good life.

The research was carried out under the control of the Indigenous community, and followed protocols for ethical conduct for Indigenous disability research. For more information about the research method used in this project, please contact the authors.



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<sup>3</sup> The data were analysed using constant comparative analysis and thematic analysis. All data were analysed using NVivo, a software package designed for data storage and analysis.



### 3. A good life for Anangu and Yarnangu with disability

#### A GOOD LIFE FOR ANANGU AND YARNANGU

A good life for most Anangu and Yarnangu with a disability means living in their community, close to family.

The primary aim of this project was to explore what Anangu and Yarnangu from the NPY Lands who have a disability consider will enable them to live the life they desire. The first step in this process is to understand what living a good life means to them.

In this report we have chosen, wherever possible, to use the voices of Anangu and Yarnangu to illustrate the findings. We have deliberately prioritised the voices of Anangu and Yarnangu people with disability and their family carers above those of service providers.

#### 3.1. Living on the NPY Lands

Repeatedly and overwhelmingly, Anangu and Yarnangu expressed their desire to live in their home community, with their family, surrounded by their language and culture. People with disability and their carers expressed their attachment to the Lands in terms of a lifelong relationship with the country around them. People described it this way:

*[This] is my ngura [homeland], my own home community. It has lots of good firewood, and very beautiful scenery. I was born here a long time ago, right here.*

*My mother and father were here, and my older brother ... set this place up and they used to work here on this farm. So, we've always been connected to the farm and so we decided to build our house here.*

A few carers suggested that people might benefit from moving to a regional centre for medical attention or rehabilitation services, but they were always aware that the person for whom they were caring would not want to go, as with this carer talking about her nephew:

*He goes to visit his family members in [a regional centre]. He goes to see his cousins. I would like him to stay there, so he can be close to the doctors, so that his doctors can keep a close eye on him and give him his injections. Sometimes he gets cranky. But he won't go, he only stays home.*

Love of country was closely bound up with the need to be with family. One person with disability stated that they were 'in a home [institution] once, and I was so sad ... so when I came home here to my home and my family I was happy again'. One man expressed



this as 'I am looking out for, caring for, my country ... Yes. And I look out for my auntie and my granddaughter, my father too and my sister. Yes. That's all.' Similarly, carrying out traditional activities such as hunting, foraging and eating bush foods was considered an important part of living on the Lands with family:

*I go often to see my family on the weekends, and we go out hunting for meat, we go hunting turkey, or anything for meat. We travel around, and then we come back home with the meat. We roast the meat and bring it back in the motorcar. We go out every Saturday or every Sunday. Like that, we go. That's what we do.*

### 3.2. Family

For Anangu and Yarnangu, being with their immediate and extended family is an integral part of life on the Lands. With the exception of four people living in supported accommodation in a community where they had family, respondents on the Lands all lived with family members. One person also received part-time support from a paid carer. Meeting up with other family members was an anticipated daily event: '... sometimes I meet up with my family at the store'.

Carers for Anangu and Yarnangu with disability who were not living in supported accommodation were, with one exception all family members. For example, a woman explained how her family supports her:

*... they [my family] put me in the bed and empty my [catheter] bag and just like that. I get put into the bed, and the children help me like that, to get into the bed.*

Family supported and celebrated the achievements of the people they were caring for. For example, a mother talked about her daughter cooking an egg:

*... she gave it me and I said, 'Hey, who made this?' And she said, 'I did!'... She was confident! She been do it good way. She made it like a woman would!*

Elsewhere, a woman lauded her cousin's major artistic success: 'It was really huge painting that he did and it looks really nice. I was so happy to see what he was doing'.

Family support is crucial in enabling the principal carer to take a break. One carer reported that the person they care for 'is staying with families in the house. I leave them in the house. Because I went for the show'. However, where other family support is not available, carers like the following young woman need to find other ways to keep on providing care:

*Oh, I don't know how I do it every day, but it's like, I mean, every morning I argue with myself, like, how do I do this? And then someone inside of me talks to me, you know? And she just tells me, 'Because you are special. You are strong. Because you have got that something that no one has'. Because, and I'm like, 'God has a reason for me to be still here. God has a reason for me to be still here and keep going'.*

Service providers also emphasised the importance of the role played by family, and the problems that could arise when family was unable to provide good-quality care. A disability worker living on the Lands commented:

*I think it's family, the main ... factor in this getting people to stay on the Lands ... So most people, they stay because their family's looking after them or ... sometimes people, they get really neglected in care.*



Regardless of the possibility of abuse or neglect, Anangu and Yarnangu respondents all expressed a desire to stay in community. Anangu and Yarnangu with disability were clear that living in community with family is more important to them than the quality of care they receive. The same woman who reported 'sometime sick pain and ... I ask my families and they don't help me' also insisted that 'this is a good place to live ... that makes me happy'.

Worried about the possibility that her daughter, who has cerebral palsy, might move or be moved off the Lands, a woman spoke about her determination to keep the young woman with her in community:

*But I don't want to give up [my daughter]. I want to look after her. Be there for her, beside her ... She is part of me, she is part of the family. I don't want to give away my daughter. I want to keep her, cause she's my kid. She is my kid. She is my future.*

### 3.3. Dreams

When talking about a good life, and how they might achieve it, people spoke about their dreams, as well as about more easily achievable desires and requests that would improve their lives. Dreams related to people's desire to overcome disability and to live an 'ordinary' life.

A woman in a wheelchair was clear: 'I want to walk around ...'. This same desire was expressed by a Western Australian man with cognitive impairment: 'I just wanna live my own life like other people'.

A man lamented the loss of his job and lifestyle:

*I went ... grading the road to every community. Making new road for trucks ... I really like. I really like work. It [becoming disabled] really stopped me ... Too hard to go. I lost my job.*

People who were not living in community talked about moving back to the Lands. A woman living in town for disability support repeatedly stated: 'I want to go back to [community]. Stay.' A senior man spoke similarly: 'I'm on dialysis, but I am worrying to go back'.

Housing was a dream for several people who were living in supported accommodation, as this would mean family could visit and stay with them. A woman reported: 'I going to ask for an old house so family can come and stay with me'. Similarly, another person in supported accommodation in a regional centre stated: 'I trying to ... get a housing. So my son can come and stay with me'. The dream expressed by another man was to own a vehicle: 'Motorcar ... Then I can go another place. Too long. Must be to the city that way. But I might get homesick!'





### 3.4. Living well

#### 3.4.1. Valued activities

##### **Occupation**

People wanted their family members to have some form of occupation – not necessarily paid, but something that offered a better quality of life for that person, and kept their mind active. A family member expressed her concern:

*She just sits there and she doesn't know what she's doing. She has no idea. You know, she looks around at the ground and we say, 'We can't leave her like that. We have got to talk to her, tell her stories, to make her brains work'.*

Several men mentioned work as a desirable activity, and families were encouraging people with a disability to take up art, either painting, *puṇu* (woodwork) or *tjanpi* (grass) weaving, so they would have some form of occupation. A relative spoke about the young woman she was looking after:

*I was thinking I might take her there to do painting at [the local] Arts Centre. It would be something for her to do, to keep her brains working, because she likes to draw.*

More than one-third of the Anangu and Yarnangu participants mentioned artwork as a valuable activity. This was either painting (usually at their local community art centre), *tjanpi* weaving or making *puṇu*. Art centres have become major supports in the lives of many Anangu and Yarnangu with disability. Some people have become well known through these activities. For others, their artwork provides a source of pride and some additional income. One carer said proudly: 'He ... has been doing a lot of paintings at the Arts Centre and he was going for exhibitions ... His family is so happy for what he is doing now'.

The satisfaction derived from artwork was obvious in the words of Anangu and Yarnangu:

*'Every morning time I been come for painting and I been make him for story, I been put him that camel, kangaroo and that tree and that goanna and I been put that water, too.'*

*'Art Centre makes me happy.'*

*'I like to paint two honey ants and other stories, like Men's stories. I like to paint different stories.'*

*'I like to sit outside beside a nice warm fire. I get help from my daughter to light the fire ... She lights the fire and I make *puṇu* and I wait here until I can sell it all. That's what the two of us do.'*

##### **Bush trips**

Anangu and Yarnangu placed a high value on other traditional and culture-related activities, such as going on bush trips, hunting, and collecting bush tucker and medicines. A woman spoke about caring for her brother:

*I buy kangaroo tails and cook them and I share them with him. I share my witchetty grubs with him. He likes to eat different things. As a child he ate all the bush foods so I make sure he gets to eat all those traditional foods that he likes.*



A Yarnangu woman with a disability talked about the bush trips she enjoyed: 'We go collect all the ashes (for mixing with bush tobacco) from the bark, sometime we go pick all the bush medicine. We make bush medicine too'.

People considered bush trips therapeutic. A mother caring for her son who has an acquired brain injury stated:

*... camping on bush trips, hunting for meat, and learning. He loves it, like cooking kangaroo tail. And he might ... his mind might straighten out, and he might think, eh ... Yes.*

### **Bush medicine**

Bush medicine and *ngangkari* (traditional healer) treatments were also important. Anangu and Yarnangu made statements like 'I want bush rub'. One mother explained her daughter's improved ability to walk:

*That ngangkari man. Fixed her up. He was really quick one ... the ngangkari comes to see us and draws out foreign objects, like sticks. Out of her, to make her a little bit better, so she can move more easily.*

### **Music**

Many carers and people with disability reported music and dance as a significant resource in the lives of people with a disability. This included composing, playing, singing, and listening to music and dance. One carer explained that her daughter 'likes to listen to music, like on the phone ... she likes to dance'. Another carer reported: '... what he likes more than anything is music and bands. He loves the Bush Bands Bash'. A man said that 'I ... always sing in the church. Read Pitjantjatjara and sing'.

An Anangu woman talked about the comfort she derived from music when her injuries were painful:

*Sometimes when I get really tired and worn out, and my spine gets tired and I can't move, I am really stuck then. It is then that I rely on my stereo.*

### **Television and movies**

Watching television and movies is another significant activity, particularly for people with limited mobility. A large proportion of the families involved in the study suggested that assistance should be available to enable people with a disability to buy items such as television sets and stereos. A woman talked about her younger brother with a disability: 'He comes over to our house to watch television. But we can't put one in his house because he won't be able to turn it off'. A man from another community reported watching the same film every day as a favourite pastime:

*He been open ... that big TV and I been tell him, 'Oh, put that movie on. That horse. From Snowy River' ... I been look, he been put [it on] every day.*

Many carers requested these items for the people they were looking after. For example, one parent reported: 'He's ok when he's home and he's got a TV, he's right. He's home watching TV. But he's got nothing now'. Another carer complained: 'I been ask for TV all the time. And nothing happen'.



## **Sport**

Sport, particularly football, was another valued occupation – attending community football carnivals, watching or coaching local games, and watching football on TV. One man who could no longer play after he acquired a disability talked about coaching the local football team into a winning position: ‘I been tell like this, “You mob play for real hard! Don’t play for slowly! Come on!” He been win now! He been get him that cup’.

Similarly, a woman talked about the importance of sport for a person she is caring for:

*Yes, football. He loves to wear football shoes. He loves to go to football because his family members come over from [another community] and he knows them and likes to see them – and he always refers to them by their oldest bush names.*

Other sports were also mentioned: ‘I like go to swimming ... and I like to go for basketball’. And one woman commented: ‘I just love the Finke Desert Race, with all the excitements and good fun of the motorbikes and car racing’.

## **Outings**

Sport trips were just one of many types of outing that Anangu and Yarnangu with a disability said were important to them – but such trips were a source of frustration when the person was unable to take part. Other activities included visiting family (often in other communities, or occasionally in regional centres), bush trips, attending funerals and, for less mobile people, just being able to get out and about in the community. More than half of the families interviewed suggested that mobility-related equipment and access to transport for local journeys were high priorities for people with a disability.

Visiting family in the local community is important for Anangu and Yarnangu. One carer reported that her relative with a physical disability loved ‘taking the scooter out. She would go out and meet family members out. She would drive around maybe, somewhere, and then come back and relax under the shade’.

People also valued the chance to go for a drive, as this man often organised for his brother:

*If [he] get upset, you know, I always take him a long way. That’s what I have done a lot of times, with my car. I take him to an outstation, 100 kilometres and still take [him] to all the country. I always show him, that’s how happy for me, happy for him and other family too.*

## **Spirituality and church life**

Spirituality and church life are highly valued in community. One man reported:

*they [church] understand me, and listen to me as I read [the Bible] ... I read one just like this one here. It makes for different ways of looking at the world, gives me room for thoughts and contemplation.*

Religion also provides a solace for people who are stressed. For a woman struggling to cope with moving off the Lands due to a lack of supports, visiting a church was crucial. Her disability worker reported that ‘some days, she might want to go to that [church] six times in one day’. Another carer said, ‘we worried and prayed to Lord Jesus and Father, our God, to protect us. We are Christian people’.



## **Shopping**

The other activity that Anangu and Yarnangu looked forward to, and that many respondents mentioned, was shopping, generally in conjunction with respite or another break from life in community. Most communities have only minimal shopping facilities. One person with a disability reported: 'I like going shopping and then coming back again, going out and about, going for one week or two weeks'. Another woman commented about her granddaughter: 'We are waiting for the mother to come out so she can go, you know, like, shopping and get any things, you know'.

### **3.4.2 What supports are needed for living well?**

As well as finding out which activities people appreciated, the interviewer asked all participants: 'What would make life better for people with a disability?' People with a disability and their carers talked about activities, basic goods and therapeutic support as being crucial to improving the lives of people with a disability.

## **SUPPORTING ANANGU AND YARNANGU TO LIVE A GOOD LIFE**

Anangu and Yarnangu can be supported to live a good life by taking part in meaningful or enjoyable activities like painting, respite care and other occupations. To live a good life, Anangu and Yarnangu need basic necessities like food, clothing, beds and furniture, as well as other support and therapeutic services and equipment.

## **Respite**

A number of Anangu and Yarnangu said that they enjoyed respite breaks in a local regional centre. 'I always come back home ... once my holiday is over', said one person. Someone else suggested that her granddaughter with disability 'can go for respite. Just for maybe two weeks, go and sit down and then come back home'.

Carers reported that they too needed a break. 'I've been asking all last year for him to go on a respite, so I can have a break. For years and years I have been asking', said one woman. Another carer emphasised that she really needed respite:

*I worry about him. If I go anywhere, he knows, and he worries until I get back. He will wander over at night to look for us and when he can't find us he'll search for us. I worry about this. I'd like to go away a bit more often but ...*

## **Provision of basic goods**

Anangu and Yarnangu are extremely practical and were highly focused on practical, helpful items that would alleviate the immediate problems that arose from the extreme poverty on the NPY Lands. Consequently, a high proportion of Anangu and Yarnangu talked about everyday items and commodities needed here and now. One service provider spoke about the importance of an organisation working on the Lands, which provides some such items for Anangu and Yarnangu with disabilities:



*They do many things. They advocate, they can help with your basics – mattresses, blankets, basics and things like that. Very important, especially you know, when other family members or community members may take those basics away from that person.*

### **Beds and bedding**

A large number of respondents emphasised the need for beds and bedding, such as swags and blankets. For example, when asked what the person needed, one participant said: 'Blanket. Give him a swag?' Another woman spoke about her relative needing a bed:

*... he did have a nice bed once, but it went all weak and saggy and now it is just all broken and falling apart. He needs a sturdy bed. He's got a big heavy body.*

In another community, a woman pointed out the importance of having a solid bed, because her partner:

*can get himself up and down if he has a strong bed he can grip onto, and help himself get from the bed or floor to a chair. But he can hardly do it because of his weakness.*

### **Clothing**

Several respondents asked for clothing. This was also a common theme when people talked about shopping and respite. One carer asked for 'warm clothes, like this jumper, a warm one and shoes'. Another woman described her daughter 'running out of clothes'.

### **Meals**

Food insecurity is a genuine problem for people with disability living on the NPY Lands. There was real concern about meals, which was a sign of the acute poverty in community. One man said, about trying to save money: 'I want to save some for when I am hungry'.

People wanted access to the meals program for their family member with disability, such as this woman, asking for a referral to the service:

*I was talking to him and [the mental health] doctor ... I forgot his name. I was talking to him ... if they can help me so [my nephew] can get lunch every day you know?*

In another community, a woman spoke appreciatively of the meals service for her nephew: 'They give him whenever they see him in the street or at the Arts Centre when he's doing painting, they give him lunch there, and also in the mornings'.

Provision of meals was seen as one of the principal responsibilities of a carer. This woman's statement reveals the quality of care given to her nephew:

*I do a lot for him, though. I make sure he has access to good food. I cook it and give it to him. His cousins and sisters give him food too.*

### **Furniture and whitegoods**

Many houses had no furniture, lacking even tables and chairs, beds, and whitegoods – including refrigerators and washing machines. 'Nothing. Empty house', said a Northern Territory woman, and a woman in South Australia echoed her: 'We have an empty house'.

In another community, a woman stated that her brother 'needs a fridge so he can have his own food'. Other people said: 'We need a washing machine so we can wash blankets and clothes'.



### **Services: therapy, home care and personal care**

Many people were receiving laundry services for blankets and sometimes clothes, and found this extremely helpful. Often families have no washing machine. Some people struggle to handle large, wet blankets. One carer stated: 'Yes, one is ok, but two is too heavy. I can't lift them. We need lightweight blankets'.

Participants suggested that a care worker could assist with transport, housework, bush trips and some therapy (exercises, walking practice) as well as personal care. A person with a disability reported that a care worker 'Fixed my wheelchair ... wash ... clean the room', and 'That disability [worker] walking beside me and I walk ... Help me'.

A woman commented about her partner, that 'he should be having help with exercising, but there are no whitefellas helping him. He gets no help'.

Another woman spoke about her sister needing an occupational therapist or physiotherapist to help her find work:

*I work at [the Arts Centre]. She'd do it too, but for one thing – her hand. She can't do it because of the hand. But perhaps with a bit of help she might be able to. Perhaps if she had physio she might be able to see an improvement.*

Another carer wanted a range of services related to daily living activities:

*Teach him to wear clean clothes, how to recognise which are dirty clothes and which are clean clothes, and how many to wear. Sometimes he gets dressed and he wears too many. He has too many clothes on at the same time ... So we want to teach him what to wear and what we need is a male to teach him. It would be better for a male to help him get washed and showered ... He needs privacy when he's being showered.*

### **Therapeutic equipment**

People with a disability felt that they would benefit from a range of equipment such as toilet and shower aids, wheelchairs and walkers, specialist beds and mobility scooters. The rough, sandy surfaces out bush become a quagmire after rain, making it difficult to use wheelchairs, particularly manual ones. Carers reported that the absence of mobility aids increased social isolation for people with a disability; and highlighted the difficulties of using inadequate equipment:

*Sometimes he has no scooter, and he shouts out for help. He goes around a bit, but in a [manual] wheelchair ... It is hot and tiring, and he finds it too hard in the heat.*

Service providers also pointed to the need for equipment that is suitable for the remote environment. One service provider worker stated: 'let's get fair dinkum about the equipment you're providing to people with disabilities and customise it to the environment that they live in'. Another worker was more specific:

*Don't give us a wheelchair for a person with a disability based on a mainstream construct, because we need the four-wheel-drive version out here. I don't need the skinny, solid, rubber tyres, I need the broad pneumatic tyres ... You know the wheelchair doesn't really work that well in the mud when it gets bogged.*

Many carers suggested that a specialist bed would be very useful, to enable people with disability to receive adequate care. One parent explained the difficulties of moving her adult son:



*We try to lift him up but we can't and often we have to leave him lying down ... he can't get up by himself. We could really do with one of those beds like we see in the clinics, ones that lift up by themselves. One like that.*

One man requested: 'Oh, Lady, I spoke to that old man and that other woman, the two of them, I told them about my need for an exercise bike'. And another couple asked for 'some help with the toilet'. There were also requests 'to fix this building. New one ... have a shower, toilet inside'.

### 3.5 Summary

In these interviews, Anangu and Yarnangu from the remote NPY Lands who have a disability expressed their unwavering desire to live on the Lands, surrounded by their families (including extended families and ancestors), their language, and their culture. Their words also reveal areas where difficulties exist, and the types of supports that may help to alleviate those difficulties.





## 4. Barriers to living a good life

The central goal for Anangu and Yarnangu with disability was to remain living in their community on the NPY Lands, or to return home to their community if they were living away from the Lands. However, both Anangu and Yarnangu and service providers identified many barriers that prevent people with a disability from achieving the life they desire.

### BARRIERS TO LIVING A GOOD LIFE

Many barriers to living a good life on the Lands for Anangu and Yarnangu related to geographic remoteness. They included lack of infrastructure, transport and support services. Culturally responsive services require a committed, consistent workforce that is well oriented and supported.

Workers need to listen, respond and act.

Broader community problems – such as poverty, violence and substance misuse – also limit people’s ability to live a good life. Systemic failures result from a lack of understanding and recognition of the particular difficulties and problems experienced by Anangu and Yarnangu living on the NPY Lands.

### 4.1. Geographic remoteness

The geographic remoteness of their home communities on the NPY Lands affected people’s lives in different ways, many of them discussed below. The desert environment and climate can frequently be harsh, as this woman expressed: ‘... everyone gets tired, and in the great heat, we can’t get out and about too much. It is too hot to walk’. Roads are regularly closed, in response to wet weather or for cultural reasons.

Anangu and Yarnangu living away from the Lands wanted to go back home and be with family. Often geographical isolation and a lack of support services were major impediments to people returning, or even visiting, as often as they would wish. The three regional centres (Alice Springs, Kalgoorlie and Port Augusta) are as far as 1500 kilometres from people’s homes.

The statement of a young carer who had returned to the Lands after many years’ absence emphasises the importance of returning to country:

*I can, you know, stay out here and look at the hills and the sun shining and smell the free air, whatever. You know, like, I am finally here. I can walk somewhere. I can go out bush.*

One consequence of geographic isolation is the limited – or complete lack of – facilities and funding to provide the support that would enable many people with disability to fulfil their desire to live on the Lands.



## 4.2. Transport difficulties

The cost of travel in money, time and human resources affects people with a disability in different ways.

The remoteness of communities and the difficulties associated with transport mean that people with a disability are often separated from other family members. Anangu and Yarnangu wanted to reconnect with family by visiting other communities or through respite, like this woman with a disability: 'she was worrying for her daughter. She want to go and visit her sometime'. People living in supported accommodation (whether on or off the Lands) wanted somewhere to accommodate visiting family members.

The pain of separation from family was particularly strong for people living off the Lands. People in this situation talked about their sense of loss and grief, but also of not being able to fulfil their responsibilities in looking after family members. This man, who has a disability, is on dialysis, and lives 1000 kilometres from his home community, explained:

*Because I am a bit worried for my grandkids, by self, no mother, never look after them ... That's why I think back. Bit worried. I'm here, in town ... When I was [in my home community], I looked after my families.*

Another person with a disability, also on dialysis, lamented that her grandchildren had not met her and did not know who she was: 'But he never seen me. "Which one is my nana, really one?" They don't know. They only kissing me on the phone, all the grandchildren'.

Attending funerals of family members is a significant obligation for all community members. Often these take place in other communities, hundreds of kilometres distant, so they present a problem for people with limited mobility and few transport options. One person with a disability reported that 'if we don't go to funerals, family get angry'.

A service provider reported the difficulties of supporting someone to obtain services in town:

*... it's hard to get this bloke into town. How do you get him on a bush bus or on a plane when you've got to lift him onto the plane? He can't do that. He can't drive [his wheelchair] around the bush bus, can't lift him onto the bush bus.*

The journey to hospital or other specialist medical appointments can often be a logistical nightmare. For example, this woman spoke about her constant travel routine:

*... then I came back I moved to here and – they were still checking on me, and I was still flying to the city, back to [a regional centre], back to here, and I am still doing that. They are still flying me out, to [the regional centre], when I get sick. Even when I am very sick, they'll be still flying me to [the regional centre], to [the city], they'll still do that.*

Geographical remoteness entails a chain of indirect costs that affect people's opportunities and lives. For instance, the availability of services is limited, and the cost of equipment repairs soars in these circumstances. A service provider gave an example:

*... prior to that ... she had another amazing wheelchair, but that kept getting corroded terribly and it would be taken down to the city to be fixed and then brought back up again on the truck. It was costing a fortune. Backwards and forwards, backwards and we were doing it, you know, sometimes four or five times in a row because things were just breaking down.*



### 4.3. Inadequate infrastructure

Community infrastructure on the NPY Lands is basic and varies from place to place. In some communities electricity is provided by a generator, while in others it is supplied through the grid. The mobile phone network is currently being rolled out in South Australian, Northern Territory, and Western Australian Lands. Phone and internet services are subject to frequent interruption.

Service providers commented on how the limited supply of housing and the poor state of roads and airstrips hinder community access and service provision. For example, a worker pointed out that ‘airstrips being closed is a bit of a barrier’.

Larger communities have a school, a clinic, an office, an arts centre, and a store that operates between four and six hours per day – and in some cases is not open on weekends. One woman pointed out: ‘We are in the desert, where there is no Kmart or something ... See, it is really hard to buy things’.

Housing is in short supply across the Lands, affecting both Anangu and Yarnangu and service providers.

#### 4.3.1 Housing for people with a disability

Many Anangu and Yarnangu were living in overcrowded conditions. A woman reported that she had 12 people living in her house, three of whom required extra care due to their disability and functional limitations. The arrival of visitors regularly swells the number of residents and places additional strain on family resources, including utilities and food. One person reported:

*We get visitors to our house, looking for something to eat. They look at what I have got and ask me to feed them, but I have to tell them to look around and see that I am struggling, and to not ask me to help them, when I can hardly help myself or my son.*

Some people did not have permanent housing. A worker gave an example:

*... we set him up with the aged care, so he gets a little bit of support from the aged care centre, a little bit of support, I think. So occasionally he might move around to different people's houses. He might stay at someone's place for six months and then, you know, go somewhere else for six months.*

Accessible accommodation and buildings are not the norm in communities. This is also true of community buildings, and of transport and vehicles such as the buses and planes that allow people to travel within and between communities. One of the workers pointed out: ‘Having a house is one thing. Having disability access, bathrooms, all that sort of stuff is another thing’. A worker described the situation: ‘there are people [with disabilities] out there who have been assessed for home modifications who live in their houses, and the modifications are not happening’.

#### 4.3.2 Housing for support workers

The lack of worker or visitor housing is a major barrier to providing services in communities. One worker commented: ‘If you don’t have the accommodation, sometimes you just can’t provide the service – you have to leave early’. Another worker explained how the



accommodation conditions affected a person with a disability returning to his community for a visit:

*When we took [a person with disability] to visit his community, we literally had to stay at the motel two-and-a-half, three hours away. The time we had ... was driving to his community for two hours in the morning, staying in the community for four hours, driving back to the motel in the afternoon, and doing the same for a few days. So, he would only have four hours each day with his family.*

Another worker commented on how some staff deal with the accommodation shortage in a community: 'Or else ... people that come out ... they might have to swag it sometimes. And then get up in the morning and work'. There is also limited office space for organisations to use while in community.

#### **4.4. Problems faced by families providing care**

Although responsibility is sometimes shared among family members, caring duties are a strain for many families. A service provider working on the NPY Lands pointed out that agencies are 'asking people to do really difficult care work in really challenging circumstances with a little or no support'.

In some circumstances, the difficulties that family members encountered in meeting the care needs of the person with disability could lead to neglect or abuse. This was reported by Anangu and Yarnangu and service providers. For example, an elderly blind woman raised concerns about returning to her community:

*'If I go back home my families might leave me, they might go out bush or somewhere, you know? But I might be staying home, by myself, you know, and that makes me nervous'.*

Older carers, who were increasingly unwell and frail, worried about who would take on their caring role when they could no longer do so. One woman spoke about her growing infirmity and her fears for her younger brother with a disability:

*If I have to go to [town] – if I get sick, which I do, I have to go there for treatment. Then I can't look after him, and I worry about my younger brother then'.*

A senior woman spoke even more strongly: 'I am ... worn out from being the sole carer for all these years, no aunties, no cousins'. She went on to express her concern for the future of her son:

*I have spent my entire life looking after him, and now I would like some help. But who would take on my son? Who can I entrust to look after him now? Who will love him and keep him as I have done? I am at a total loss now as to what to do. I do not know what the future holds. I am getting too frail to look after him anymore. I am sorry but I am finding it too hard to look after my own son.*

#### **4.5. Availability of services**

The transport and infrastructure problems discussed above reduce the availability of services in community. Anangu and Yarnangu requested a range of services that were either limited or unavailable in their communities.



Several women requested assistance with housework, a service that is not provided in community. One carer pointed out: 'I am trying to get help with the housework, sweeping and mopping and keeping the place clean'.

A woman wanted to place her son in an independent-living centre, because of the care assistance provided to people living there, which she was unable to obtain when he was living at home. 'No, no no. That worker only help the people living at the independence house. Not outside'.

One service provider talked about a community where there were:

*really minimal services ... I went out once a month... the OT [occupational therapist] and physio [therapist] came up ... every three months to that community and there's a family looking after a cranky old guy with a ... below-knee amputation.*

A remote worker pointed out the lack of services to support families caring for disabled family members:

*... in mainstream, if I had a disabled brother or sister or a child, that was in a wheelchair, I would get so much support ... I would have a nurse come in and help me with their showering. I would have a little bus come and collect them to take them out for activities during the week. I would get lots of respite time. But Anangu families don't get any of that, really, within the community ... I suppose, it's like anything in remote, it's expensive.*

Anangu and Yarnangu requests for therapeutic support, in part, were limited by their lack of previous experience of services. Even though many carers did not identify a need for specific supports and other services, service providers often considered that the family member with a disability would benefit from additional services. A carer of a person with disability said that her daughter 'cramps sometimes. Sometimes there is pain. We want to get [her] to move. To get exercise. Someone to help her with that'.

Similarly, a disability worker expressed his frustration at the lack of services:

*We have a physio that flies in for three days once every eight weeks or an OT that flies to Alice Springs, and if somebody needs the service, they have to get their way ... there, to catch the bush bus [to Alice Springs].*

Service providers spoke of the need for a wide range of services that were unavailable, including 'access to a gym', 'a physio, an OT, a speechie [speech therapist], psychologist, neuropsychologist in the Lands'. One service provider explained that obtaining diagnostic services is just as difficult:

*... but initially for diagnosis – so, they need to be able to be flown out and, and, and ... when you're looking at a wait list of two years to get a MRI [magnetic resonance imaging] and a baseline neurological assessment, triple that for somebody from the APY Lands where you've got to get funding to get them onto a plane to ... be brought down to [the city] for a particular appointment on a particular day.*

An agency worker summarised the situation for Anangu and Yarnangu: 'But then actually, there ... actually aren't choices at times'.

Consequently, the lack of support services for people with complex needs has led to a number of people living in supported accommodation, located off the APY Lands. A woman in a wheelchair who is in this situation because of the minimal support available at home was quite clear: 'I want to go to [my home community] and stay in [my home community] for ever'.



## 4.6. Workforce problems

Workers often failed to meet the expectations of Anangu and Yarnangu with disability living on the Lands. People with disability were frequently disappointed by the low levels of engagement, poor service provision and, ultimately, lack of improvement to their quality of life. Indigenous culture focuses very much on relationships with family and community members, and people regard having a relationship with workers and service providers as extremely important. However, the opportunity for trusting relationships to develop between Aboriginal families and service provider staff is limited by a number of workforce problems.

### 4.6.1. Staff turnover

One obvious difficulty resulted from the high level of staff turnover. No worker means no services. Anangu and Yarnangu are only too aware of this, making statements like ‘She’s gone. She’s in the city. Yes ... nobody doing that today’.

The high rates of staff turnover also reduce people’s ability to form the trusting relationships with workers that are important to Anangu and Yarnangu. One carer talked about her mother needing someone:

*... who is really kind to her and will take her out. You know. That’s when ... she starts trusting that person. That’s when it builds up and she will say, ‘Hey, you are a good person! I like you! I want to go out with you’.*

In addition, people are required to tell and retell their stories to each new worker. As one worker pointed out, it’s ‘really exhausting and it’s really upsetting for families to have to tell that to every new person that ... is involved... You know, they’ve got some shame associated with it’.

Anangu and Yarnangu commented on the lack of availability of support services, such as physiotherapy, in terms of the lack of workers. For example, one person with a disability stated: ‘I want ... someone to help me and exercise’.

Service providers also found the rates of staff turnover frustrating. A worker explained:

*So, doing ... collaborative case work ... you can just be getting something up and running and then one person will leave and so the whole case plan kind of falls in a heap. And then you’ve got to ... try get it up and going again with the next person ... we’ve had referrals come to us that we’ve not been able to follow up on for that reason.*

Discussions with workers about staff turnover considered the factors that workers on the Lands found particularly difficult. Major problems reported included lack of personal safety, long hours of travel, and frustration with poor client results. In addition, those workers living in community reported a sense of isolation from family and friends, lack of workplace support, lack of facilities for recreation or for their children’s education, and burnout.

On the other hand, the factors that kept people working in communities ranged from commitment to ideals such as social justice for a minority group or helping people in need, to enjoying the relaxed lifestyle in local regional centres and developing rewarding relationships with community members. Work-related benefits included being part of a supportive team, celebrating the small successes, and having more autonomous working conditions. People also enjoyed the variety of tasks and experiences encountered from day to day, and the opportunity to develop a range of skills.



#### 4.6.2. Short or irregular worker visits to community

Workers whose visits to community were brief or inflexible could provide only a limited service. One woman reported that she ‘... always miss the workers. They come around and I’m always up that way [somewhere else]’. Many workers in community also saw this as an obstacle to offering a service. A worker explained:

*No, most of those more specialised, whether it be psychiatric or physio, OT, paediatrics, they’re often fly-in, fly-out or drive-in, drive-out and they’ve got the whole ... range of the communities to cover so they come in and they’re there for like two hours that morning and I’ve got to get to the next clinic by that afternoon so that I do the afternoon block there’.*

One worker complained that their biggest dilemma was: ‘how do I support people that I only get to see maybe once or twice a year?’

#### 4.6.3. Working with Anangu and Yarnangu

Another problem was apparent in the Anangu and Yarnangu view of appropriate ways for workers to meet, talk and work with people. Anangu and Yarnangu emphasised the need for workers to spend time with the families and people they had come to see:

*We don’t want the people to just come here see the person and ... just go away again. We want someone to come here and talk good way and help. That’s what we want, you know? Talk to my daughter. Tell us what to do ... what they have to do for us when we tell them what we want. This is what she wants.*

The theme of workers being interested, kind, and really listening and responding to the needs of people came up repeatedly for Anangu and Yarnangu:

*We want kind people to come. To take them [people with disabilities] around to places, like the creek or something, to cook kangaroo tail and potatoes, in the afternoon. Kind people to talk to them nice way. Friendly. Not just coming here and giving a talk and then go. Useless. That’s useless. No good.*

One woman made a plea for workers to ‘Just sit down and listen to the family, to the patients. If they are saying there’s something wrong, then listen and find out’. She talked specifically about workers not listening to family concerns about her brother, who had:

*ended up burning a house down. And a bit of his leg was burnt. But he didn’t know he was doing that, because in his mind he didn’t know that was wrong.*

Another woman pointed out that workers ‘have got to be patient, too’, pointing to the need for workers to understand and fit in with the slower rhythm of life in community. ‘If a person is, you know, busy, they got to have patience. You know, wait around and come back later’.

#### 4.6.4. Challenges in developing and expanding the Aboriginal workforce

Anangu and Yarnangu reported to service providers that they are happy to have Aboriginal staff provide personal care or interpreting services only when it is culturally appropriate for them to do so. The wrong worker can be interpreted as an invasion of family privacy.

In many communities, Anangu and Yarnangu work with people with disability in roles including *malpa* worker, Aboriginal health worker, and providing meal services. Service



providers described recruiting local people as an investment in local knowledge, skills, and social and cultural understanding. Many reported that they use local people to help build a culturally safe environment for working with Anangu and Yarnangu. However, employing community members to provide personal care would require structured training, support and supervision, as well as a degree of flexibility to cater for some of the cultural factors likely to arise.

The complexity of relationships between families in community can lead to difficulties if another community member performs intimate services for a person with a disability. Such difficulties may be caused by conflict between families, or a sense of shame at another person filling this role (with the implication that the family is not fulfilling its obligations). The situation can also breach cultural protocols that may not apply to someone who is not from the Lands. As a result, several community members express a preference for a non-Indigenous carer to do this work.

Anangu and Yarnangu prioritise personal and family business over work commitments. This can lead to absenteeism for reasons that may seem questionable to service providers. Local Aboriginal workers occasionally risk being insulted for taking on work in this way: “Are you turning into a whitefella?” Yeah because she’s got a job’.

#### 4.7. Community issues

In remote NPY communities, people focus on their immediate and pressing needs, such as food, shelter and safety, rather than on longer-term problems. This is reflected in the earlier discussion of the importance of food and meals in Section 3.4.2: Meals. Such worries contribute to elevated levels of family stress and violence. In such situations, people with a disability are particularly vulnerable. A man with a disability had to move houses, because ‘People fight over food in that other house’. A worker commented about a community member who:

*... constantly comes in and tells me that she’s hungry and she’s got no money. And I said, ‘What happens to all your money and your food?’ And she said, ‘Well, I buy food and people just come and take it out of the fridge’.*

In some cases, people reported that other family members were taking their disability support pension, or that the carer pension was going to someone who was not supporting the person who had a disability. A worker summarised the effect of living in poverty: ‘there’s loads of goodwill, but people are so stretched ... just keeping people ... alive and fed is probably the best that happens’.

Sometimes people have acquired a disability from fighting or violence. For example, this woman was blinded as a result of family violence: ‘... my partner been hit my head. Because the blood was bleeding and I couldn’t feel that. Then my eye went funny, it was yellow and brown, you know?’

Another person with disability had been ‘kicked out of the community and told that he couldn’t return because he perpetrated violence ... repeatedly’. This was not an isolated case. The limited resources in community heighten the vulnerability of people with a disability. A woman who had moved to a larger community for treatment was upset that, in her home community, her house had been broken into and the contents stolen, including the stereo belonging to her daughter who has a disability. She stated: ‘They been break in.



Got everything. Mattress and all. And the stereo player'. The mother of another young person with an intellectual disability pointed out: 'She just get wild, you know, when somebody steal her things. She hit herself'.

Despite these difficult conditions, people choose to live on the NPY Lands with their family. This was clearly articulated by a disability worker discussing a person living off the lands who had spent a month on respite in community:

*Family are going and spending all her money on food and she might not be getting enough ... But that month, for all its vagaries and its difficulties ... is still the best month that she's had in years.*

#### **4.8. Substance misuse**

Another difficulty is the level of substance misuse and its effect on people with a disability. Inhalant abuse has been responsible for widespread brain injury on the Lands.

For example, a mother talked about her son's brain injury: 'he was sniffing, and from sniffing he start ... He was still sniffing, and then he ... start smoking gunja [marijuana], and from there I was still looking after him'.

There is also intense pressure on families when money is being spent on drugs, such as marijuana. One mother gave the example of the son she was caring for: '... he got his money on Tuesday. Five hundred and fifty. And he done little bit shopping. And you know how much he saved for me? Twenty dollars. And all the rest went to the gunja'.

One of the people interviewed talked about the violence that could result from smoking marijuana:

*She and me too am frightened for family smoking marijuana too much. She been come around and told me 'My brother been hit me but ... marijuana, he's smoking marijuana'.*

#### **4.9. Cross-cultural factors**

##### **4.9.1. Building relationships**

Indigenous culture focuses very much on relationships, particularly with family and community members. For this reason, people are most comfortable working with services where they can build up a relationship with the workers. As already mentioned, services whose workers fly in and out of community every few months do not meet this need. This difficulty is made worse by the high staff turnover that is a feature of services in Central Australia.

##### **4.9.2. Planning for the future**

Traditionally, Anangu and Yarnangu live from day to day and do not plan for the future. A woman from a remote Northern Territory community expressed this:

*Planning future is a risk, you know. If we plan the future now something will happen, like family passing away, and all that. That's get, hold us down. But really, in our culture and custom we don't really plan for the future. No, it's something new in our system, you know. We've got to learn about future.*



This approach reduces people's ability to plan for their own future and their children's future. On a smaller scale, it makes them less able to manage their finances, or in many cases to think about the consequences of their actions. For instance, a service provider reported that one of their clients 'every year ... was taking her ... \$20,000 wheelchair and putting it under the showers at the pool to cool down'. Understanding this approach to life is crucial for people working with people and their families in community, and suggests a need for in-depth cultural orientation of workers.

#### 4.9.3. Disability and shame

Another issue for people with a disability is the stigma associated with being disabled. The family of one young woman with cerebral palsy reported that she was ashamed of being seen in her electric wheelchair, so she only used the ordinary manual wheelchair around community. She would use the electric one only on short 'bush trips', out of the community where the softness of the ground necessitated its use. A couple of families reported that people were too 'shy' to take part in some activities. One Anangu commented: 'Too many eyes looking that way, looking at her. She doesn't want to get upset or ashamed'.

Closely related to the sense of shame is a social taboo, among people living in remote communities, against appearing different. As one worker put it:

*I've had other family members tell me, 'he doesn't want to look different'. But I've never heard that from the client themselves ... I have had a few families say, 'no, oh, no he doesn't want to shame'.*

A dietician talked about people refusing special diets:

*So, the clinic actually found a way around how to get thickened fluids in. But then there's the whole problem of how do I get the person to use it? Because there's this, I don't know if it's a cultural thing, but there's this whole 'I don't want to look different' thing.*

#### 4.9.4. Communication

Traditional culture on the NPY Lands is orally based, so documents were unknown. Consequently, people who are faced with bureaucratic requirements – in applying for a disability pension, for instance, or seeking assistance from the NDIS – have difficulty in negotiating those processes. People asked for help, as in:

*I got a letter for my nephew so if someone can help me and fill in for him. I got a form at home if you can help me out? For him so he's, he gonna be in Disability?*

#### 4.9.5. Cultural priorities: allocating goods and resources

Anangu and Yarnangu generally allocate goods and resources according to cultural priorities. This philosophy is often applied to resources such as carer payments. Several people who were caring for someone with disability said they were not receiving the carer payment – that it was going to someone else. Because the responsibility for caring for someone can be fluid, and the processes to adjust payments through Centrelink are lengthy and complex, this situation causes a lot of dissatisfaction, as in this instance:



*I am the carer for my brother, because I am the real sister from one father and one mother. I should be getting the carer money for him, not anybody else. What happened to that carer money?*

#### 4.10. Systemic problems

Service providers have reported many systemic barriers that prevent them from supporting people with disability to live a good life. At the everyday level, a lack of flexibility in the services they can offer creates distress for many people with disability. Many workers commented that some agencies are not flexible in supporting Anangu and Yarnangu. One example involved meals:

*One of our clients in one of the communities said he didn't like the agency meals. He's like 'I don't like this meal' and that's last December ... he refused to eat it ... and then the clinic noticed and they said 'Oh this guy getting skinny'. And he's really skinnier and skinnier, and he refused to eat any of the agency meals and then I had a chat with the person who does the meals, and she said, 'Oh no, we can't really separate, make a special meal for this person'. So, the services, they don't really see what the person wants and then try and work around that, trying to support [them]. 'We do it that way and ... if you don't want it, that's your problem'.*

Anangu and Yarnangu have a holistic view of life. For this reason they find the way that mainstream systems of assistance for people with disabilities are divided and categorised to be illogical, inflexible and confusing. One of the workers expressed the overwhelming complexity in this way:

*Sometimes people come to me with problems and I start going through the agencies and I meet brick walls as well. And then I just think oh my gosh, if it's this hard for me, how hard is it for them? I mean, you know, at least with me if I meet a brick wall I think, 'Okay, wait ... stop. Who do I need to speak to, how can I get around this? What other way can I tackle it?' They haven't, people out here don't have any idea what's available to them, what's potentially available to them or even who to ask about it.*

Many Anangu and Yarnangu with disability experience lengthy delays in receiving services, processing referrals, or receiving or modifying special equipment. Workers are also aware of this unsatisfactory situation, but are often constrained by organisational policies, limited resources, and their conditions of employment.

Other difficulties are caused by the routine supply of community buildings, including houses, that have no disability access. In addition, it is common for people with disabilities to move houses within a community. This cultural practice increases the cost incurred by service providers for modifying homes. One worker stated: 'one of the problems is that you can refurbish a house beautifully for an Indigenous person, and they've moved house the next week'.

The effects of the limited services available on the Lands are exacerbated by the fact that the Lands lie across three Australian jurisdictions. Some cross-border inconsistencies or lack of coordination create inequities in service access and provision. One disability worker said: 'they can see that someone 30 kilometres across the border is receiving X, Y and Z and will ask, "Why can't I have that?"'. Health system records are not generally shared across State borders. A worker pointed out: 'Two communities may be 30 kilometres apart, but because it's a State border ... someone over here, this clinic can't gain any access to their medical records'.



#### 4.11. Summary

In order to live the life they desire, Anangu and Yarnangu with a disability must overcome many obstacles, documented here in their words and in those of their family carers and service providers. Geographic characteristics and inadequate infrastructure, together with broader issues such as poverty and violence in community, can all cause problems. There are also concerns about ways of working with service providers and the limited availability of services on the Lands.





## 5. Implications for the National Disability Insurance Scheme (NDIS)

This report discusses how Anangu and Yarnangu with a disability living on the NPY Lands would like to live their lives. The implications of these findings will be important in rolling out effective and culturally appropriate services and supports for people with disabilities in remote communities. Many of the examples in this report illustrate that people living in the remote NPY Lands are a long way from receiving the person-centred services that underlie the NDIS philosophy. These examples also illustrate that Anangu and Yarnangu have little choice or control over the disability supports and services that they do receive.

Our research findings have implications for the NDIS and for other government-funded programs, such as health care and community infrastructure. Implementation of the NDIS is likely to exacerbate some of the challenges to living a good life. Several workers expressed concern that the coming national reforms would reduce flexibility and increase the fragmentation of services on the Lands.

The NDIA works on the assumption that all people with a disability start from a baseline where their basic needs are met each day, that everyone has a moderate level of literacy, and that a wide range of services is universally available.

The findings of this research make it clear that, on the NPY Lands, this assumption is false. For Anangu and Yarnangu, the need for basic resources (food, bedding and basic goods) must be satisfied first. Only then can people consider the more complex and less immediately urgent needs that result directly from their disability or the disability of someone they are caring for. People on the Lands speak English as a third or fourth language and many have limited literacy. For these reasons, they find it difficult to negotiate bureaucratic systems without extensive individual advocacy.

This report has also shown that only a limited range of services is available to people on the Lands. Anangu and Yarnangu have said that they want culturally responsive ways of working with those services, including the NDIS, to enable people with disability to live a good life. The NDIA needs to take these considerations into account when developing its policies and service protocols for people living in remote communities.







## 6. Culturally responsive services: conceptual framework and recommendations

This research focused on what is needed for a good life for Anangu and Yarnangu from the NPY Lands who have a disability. Every day, people with a disability, their carers, and their service providers on the NPY Lands face complex and constantly changing difficulties and obstacles. These make it difficult to develop a single model of service that will enable Anangu and Yarnangu with disabilities to live a good life.

Supporting a good life for Anangu requires organisations and workers to ‘listen, understand, respond, and act’, so that people have choice and control over their lives. In other words, service providers must have the flexibility to respond to each person’s particular needs, if they are to help Anangu and Yarnangu with disabilities to live a good life.

The principal findings and the recommendations from this report have been incorporated into a three-part conceptual framework: *Heart* (emotions), *Head* (knowledge), and *Hands* (actions). This framework, derived from work by Rippon and Hopkins,<sup>1</sup> was suggested by the information gathered, and is useful for all agencies that provide services on NPY Lands. The three elements of the framework overlap and are interrelated, so each recommendation is listed here under the most relevant element.

### 6.1.1. Heart

Anangu and Yarnangu with disabilities want to stay on country with family and culture, taking part in meaningful activities and interacting with family members and trusted service providers. Anangu and Yarnangu with a disability who are living away from the NPY Lands want to return to the Lands. With few exceptions, all of the care for Anangu and Yarnangu with disabilities on the NPY Lands is provided by family. Therefore the wellbeing of family carers is essential to enabling Anangu and Yarnangu with disabilities to remain on the Lands.

- Family carers on the Lands need support in a range of ways, including:
  - a flexible respite model that provides a break when needed, either on or off the Lands
  - assistance with caring for the person with disability
  - domestic and laundry assistance.
- People with disability need support to participate in cultural, family and community activities, including appropriate equipment and transport.
- Anangu and Yarnangu with a disability who are living away from the NPY Lands need to return regularly to the Lands, whether through more flexible respite options or other specific programs.
- Long-term, consistent services are needed to enable Anangu and Yarnangu who have disabilities to build trusting and respectful relationships with workers.



### 6.1.2. Head

All interactions between Anangu and Yarnangu with disability, their carers, service providers and policy makers should be based on internationally recognised human rights and responsibilities. Regardless of geographic location, all people with disability should be able to obtain culturally appropriate support and the services they need to live a good life.

- Policy makers and service providers need to acknowledge and respond to the particular strengths, circumstances and difficulties faced by Anangu and Yarnangu with a disability living on the NPY Lands, in all policy relating to those areas.
- Anangu and Yarnangu with a disability need flexible services that are responsive and culturally appropriate.
- Anangu and Yarnangu need to guide policies and practices for disability support on the NPY Lands. To achieve this:
  - Policy development needs to begin with listening to Anangu and Yarnangu. Policy makers need to also continue to seek regular feedback.
  - Organisations working with people in remote communities need to involve Anangu and Yarnangu in all levels of their operation, from board members to workers, to ensure appropriate cultural guidance and feedback.
- Anangu and Yarnangu and service providers need to work together to better understand each other's expectations of the carer role.
- Policy makers and service providers need to develop and implement strategies to ensure quality orientation, cultural training and support for disability staff working with people on, or from, the Lands.
  - Continuing cultural responsiveness needs to be facilitated through mentoring by Anangu and Yarnangu.
- Policy makers and service providers need to always use interpreters when working with Anangu and Yarnangu.
- Policy makers and service providers always need to work with Anangu and Yarnangu to develop a common understanding of appropriate roles for a local workforce to assist people who have a disability.
  - These need to consider a wide range of roles, including carer support and equipment maintenance.
- Organisations need to take a long-term approach to developing the workforce, both Aboriginal and non-Aboriginal, that recognises and provides appropriate levels of engagement, education and support.
- There needs to be flexibility in the processes, management and costing of the National Disability Insurance Agency (NDIA) to respond to the particular difficulties faced by people with a disability living on the NPY Lands.
  - Representatives of the NDIA need to consult regularly with Anangu and Yarnangu to ensure all people with a disability receive the full benefits of the National Disability Insurance Scheme (NDIS).



### 6.1.3. Hands

The first priority for Anangu and Yarnangu with disability and their carers is to obtain basic necessities. They also want to take part in culturally appropriate, meaningful community activities. Support for these requirements and activities need to be provided by a caring, skilled, culturally responsive and well-resourced workforce that includes both Aboriginal and non-Aboriginal workers.

- Anangu and Yarnangu need help with basic goods and services, including:
  - meals
  - bedding, clothing and basic household goods
  - domestic assistance
  - equipment and supports such as basic therapeutic assistance, assistance with activities of daily living, transport, and life-skills training.
- Anangu and Yarnangu are entitled to and need equal access to services, including:
  - allied health services, equipment and support
  - diagnosis of and support for cognitive and neurological disorders
  - mental health services
  - drug and substance-misuse services
  - carer support services.
- Community infrastructure needs development so that workers can stay on the Lands for extended periods of time and develop the trusting relationships that are crucial in working with Anangu and Yarnangu with a disability.
- The responsible agencies need to ensure that all new buildings on NPY Lands meet universal housing standards, so they are accessible for Anangu and Yarnangu with disabilities.





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## Abbreviations

APY	Anangu Pitjantjatjara Yankunytjatjara
HACC	Home and Community Care program (These services are currently accessed ... through the Commonwealth Home Support Programme)
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NPY	Ngaanyatjarra Pitjantjatjara Yankunytjatjara
NPYWC	Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council (Aboriginal Corporation)



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## Appendix

### Walykumunu Nyinaratjaku: To live a good life

#### Trigger questions for Anangu and Yarnangu

Tell us about the place where you live

*Tjalkutjurani ngura nyanganka nyuntu nyanganyi*

What are the good things about this place?

*Ngura nyanangku wiru nyaa ngaranyi?*

What are the things that give you problems about living here?

*Nyaaku nyuntu nyanganka nyinanyi?*

Is there somewhere else you would rather be living?

*Nyuntu mukuringanyi ngura kutjupangka nyinyanytjikitja?*

Have you been living here for a long time?

*Nyuntu ngura nyangangka iriti nguru nyinani?*

When did you come here?

*Yaalara nyuntu pitjangu?*

Where do you usually live?

*Nyuntu yaaltjingka mula mula nyinangi?*

Is that where you want to live? (i.e. back there)

*Nyuntu mukuringanyi malaku angkutjikitja?*

Do you live in (visit?) other communities or towns?

*Nyuntu communities munu towns kutjupangka nyinanyi*

Where does the rest of your family live?

*Nyuntumpa walytja tjuta yaaltji nyinanyi?*

What are the things you like to do?

*Nyaa nyuntu angkula palyantjikitjangku?*

What do you do most days?

*Nyaa nyuntu tjintu kutjupa kulini palyantjikitjanku?*

Are there things you want to do but can't?

*Tjana kulini nyuntu palyanytjaku palu putu kulini palyanytjikitjangku?*

Do you have many worries?

*Nyuntu kulintja pulka kanyini?*

What causes these worries?

*Worries nyaa purinypa nyuntu kanyini?*

What would make your life better?

*Nyaa nyuntu kulira palyaringkuku?*

*(Tjana wangkanyi ka nyuntu ma wangka tjana. Nganana kutjupa kutjupa palyantja wiya)*

Who helps you in the community?

*Nganalu nyuntu nyaa helpamilani community-ingku kutjupa kutjupa uwankara tjungungku?*

Are these the people you want to help you?

*Munta tjana nyanga nyuntu nya helpamilangku?*

What kind of help do you need?

*Nyaa purinypa palyanytjaku helpamilantjaku nyuntu mukuringanyi?*



## Trigger questions for service providers

From your professional experience, what are the key factors that enable Anangu and Yarnangu with disability to live the life that they choose?

If you can, give me an example of an Anangu or Yarnangu with disability successfully supported to live a life that they choose? Is this person's experience unique or common?

Can you explain what the barriers were or are and how they have been overcome?

What are the main support structures in the home and community?

Who in the community provided the main support/care?

If you can, give me an example of an Anangu or Yarnangu with disability who is not successfully supported to live a life that they choose? Is this person's experience unique or common?

What are the barriers that prevented this person from living the life they desire? If so, can you explain them?

Are there mechanisms that could be put in place to help that person live the life they choose?

In your experience, what factors are essential to enable Anangu or Yarnangu with disability to live the life that they choose?

What roles do non-disability service providers play in enabling Anangu or Yarnangu with disability to live the life that they choose?

Are specialist/mainstream services/programs needed in the communities to enable Anangu or Yarnangu with disability to live the life that they choose?

If so, what types of specialist services?

How would these services enable Anangu and Yarnangu with disability to live the life that they choose?

In your experience, what factors are essential to establish clear pathways for Anangu or Yarnangu with disability to access your community services/programs?











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