

Perspectives of Aboriginal people on disability and care in the Barkly Region of the Northern Territory

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1.0. Introduction

The purpose of this report is to describe the process and results produced by Ninti One through research to help determine effective support arrangements for Aboriginal people with disabilities living in the Barkly Region of the Northern Territory.

The purpose of the research, which was commissioned by National Disability Services as part of a national disability workforce project, is to understand:

- 1) How care and support is currently provided to people with disabilities and the different roles played by families and services.
- 2) What people with disabilities think about the support they receive now, and what they think would improve their wellbeing if they could choose more support.

This research aims to capture perspectives and insights of Aboriginal people with disabilities and their carers. It makes use of ethnographic methods, such as observation, case studies and stories as a means of exploring the lives, interests and priorities of people with disabilities and their carers in the Barkly Region. Specific themes explored through the research include:

- The capability and situations of people who provide support to people with disability (ie are in a person's circle of support)
- The extent to which individual advocacy is undertaken or may be needed
- The individual aspirations of carers especially in relation to employment, training or assistance with undertaking care.

Overall, our intention throughout the research has been to enable participants to voice their own priorities, needs and stories. The analysis of the information collected in Ali Curung and Tennant Creek has led us to identify key themes that represent those voices in this report.

2.0. Methods

2.1. The Barkly Region

The focus of this research is the Barkly Region. According to the Australian Bureau of Statistics and Barkly Regional Council, the region is the second largest local government area in Australia, an area which is approximately 323,514 km², 42 per cent larger than Victoria.

The largest settlement in the region is Tennant Creek, with a population of 3,560 including associated developments and town camps (sometimes more formally known as community or urban living areas). Tennant Creek has several town camps in which some of the research described in this report was conducted. Town camps are settlements generally located on the edge of town, comprised of residential rental properties managed separately from other housing. Town camps are occupied entirely by Aboriginal people, which in Tennant Creek generally means Waramunga and Warlpiri people. People spend a lot of time using their yards as living areas and some individuals and families prefer to cook, eat and sleep outside. Houses in town camps are often overcrowded. By mainstream standards, conditions are often poor, with the need for repairs and upgrades often evident.

Ali Curung is one of the largest Aboriginal communities in the region, with 535 people. The total estimated resident population of the Barkly region is 8,137 (ABS – Northern Territory at a Glance 2011), which means that around half of the total population of the region lives in Ali Curung and Tennant Creek. The average population density of the Barkly Region is two people per 100 square kilometres. Tennant Creek is located on the Stuart Highway approximately 1,000km south of Darwin and 500km north of Alice Springs. Ali Curung is 170km south of Tennant Creek and around 20km east of the Stuart Highway.

According to Barkly Regional Council, around 50 per cent of the total population over 15 years of age speaks a language other than English at home. Many Aboriginal people in the region speak several Indigenous languages with English frequently being a third or even fourth language. Some of the larger language groups in the region include Warumungu, Warlmanpa, Warlpiri, Jingili, Garawa, Mudburra, Kaytetye, Alyawarr, Anmatyerre and Wambaya. The name Ali Curung is an adaptation of a Kaytetye word for 'dog dreaming'.

In summary, the Barkly Region is characterised by a small population distributed in a small number of communities across a very large area. For Aboriginal people with disabilities and their families and carers, the region has particular features that are relevant to their quality of life including access to services, long distances between settlements, mobility within a harsh environment and the complexity of both the bi-cultural (Aboriginal and non-Aboriginal) context and also the many different language groups that make up the Aboriginal population.

2.2. Ethics approval

Ninti One submitted an ethics application to the Central Australian Human Research Ethics Committee (CAHREC) on 27 March 2015. On 28 April CAHREC notified Ninti One that it had granted conditional approval for the project, subject to three issues of concern relating to the length and detail of the Information Sheet and letters of support being addressed. Ninti One submitted documentation addressing these issues on 4 June and final approval was received from CAHREC on 16 June 2015.

The research was conducted in a way that ensured respect for privacy, including the following statement in the Project Information Document provided to all participants:

‘No-one but the nominated researchers will have access to the raw information provided by the participants. We will record what community you live in, your gender and age range and no other identifiable information. We will not record anyone’s names and we will not collect any information that will be able to easily identify the people who are part of this project. We will not use or publish your name or anything that will allow other people to know who you are from this research.’

This approach to the interviews enabled participants to feel they could openly share details of their circumstances and needs. It improved the quality of the final analysis and results.

2.3. Recruitment of research team

The research process began with a visit of Tammy Abbott, Senior Research Officer to Tennant Creek during 27 and 28 April 2015 where she met with Angela Teasdale, Workforce Project Coordinator at National Disability Services. The meeting discussed the scope of the research, the proposed interviews and focus groups, recruitment of Aboriginal Community Researchers (ACRs) and to share information to assist with the practical aspects of the work, such as identifying the participant cohort and relevant service providers in the region.

Tammy returned to Tennant Creek on in late May with Lena Taylor to provide induction and training for the new ACRs and to prepare them for the work. There were four people present at the induction and training sessions. They were Stella Raymond, Noeleen Nelson, Levina Johnson and Dianne Dickenson. Together we mapped out where and who the cohort participants would be. The ACRs were already very familiar with the cohort group and where they lived. They worked out who was appropriate to conduct interviews with them, both to observe cultural sensitivities and to meet standard Ninti One practice, especially when working in remote Aboriginal communities or towns with a large Aboriginal population.

Following a serious violent incident in June, sorry business (grieving in the community) impacted greatly on the ACR group, meaning that two out of the four trained researchers had to withdraw. We were successful in recruiting a male ACR, Dean Williams who has a wealth of knowledge and experience. Dean was quickly able to learn the process and work with us.

The second cycle of research took place in October 2015. Tammy was joined by Steve Fisher, Technical Advisor, and a further ACR was recruited, Coleen Wright who worked with Tammy, Steve and Noeleen Nelson.

2.4. Research cycles

In our community-based research, Ninti One has frequently found that Participatory Action Research (PAR) is most effective. Instead of a linear approach to collecting data for analysis, PAR uses an action-based process that encourages reflection at points during the research. The approach we take to PAR has several advantages:

1. It permits collaborative design involving Aboriginal Community Researchers
2. It uses cyclical research, meaning that the findings of one cycle contribute to the next.
3. The method enables adjustment to changing knowledge and circumstances as the research proceeds as it does not rely on a design that is fixed at the outset.
4. It emphasises all learning relevant to the research objectives to be valuable, therefore enabling the research team to pursue leads and interesting avenues as they arise.
5. It focuses on building depth into the research over time, leading to high-quality results.

The cyclical research process typical of PAR enables the results from one cycle to inform the approach to the next. For the Barkly project, the first cycle involves interviews with people with disabilities and the second introduced other methods including focus groups with carers. The cumulative effect was to build insights and knowledge from the first cycle into the work of the second.

The plan for the second cycle of research was as follows:

- 1) Generation of deeper insights through further discussion with four participants through a second interview with them to explore subjects of interest that emerged from the first cycle. Examples include advocacy, personal goals and the way in which disability affects their cultural needs. This needs to also include more in-depth discussion and description of the situation and concerns of people caring for the people with disability and by spending time with carers and family, paid and unpaid.
- 2) Case studies with four participants involving spending a typical day with them, accompanying them on their usual routine, meeting the people with whom they interact and gaining more comprehensive insights to be written up as a 2-3 page case study for each person. These people will be different to those who are the subject of 4 below. Here too the focus would be on the work of care, not on disability per se.
- 3) Collection of stories from at least six individuals using Most Significant Change (MSC) methods. This approach would generate responses to

questions such as 'Tell us about a time when something changed for you in a positive way', linked to the way they are being supported – not their situation generally.

In practice we encountered a constraint to the second component of this plan in that many people we approached considered their lives to not be interesting enough for researchers to spend extended periods with them. The experience would be one of 'shame' for them. Instead, they felt that what we asked them in an additional interview would tell the researchers all they needed to know. In addition, we found that certain people were not able to engage in a conversation for any length of time. They appeared tired, confused and shy about talking with us, even when our approach was very cautious and gentle.

These two factors led us to revise and ultimately improve the methods used in the second cycle. We decided to invite carers to two group discussions held at the offices of the National Disability Insurance Authority (NDIA) in Tennant Creek. Thanks to the efforts of Coleen and Noleen in locating people, inviting them and then providing transport, we attracted 12 people to the two groups. Five of these participants had been interviewed in the first cycle, with seven people being new participants. The benefits of the group discussions were:

- They enabled people to share experience and knowledge, often adding new insights through collective thinking.
- They allowed our Ninti One researchers to introduce examples and stories collected through the MSC process and hear other people's perspectives on them.
- They were a place to which people had to travel, even if short distances, but was away from the pressure and intrusion that people can sometimes feel when interviewed in their own homes.

So, although a change in method was required, we feel that we arrived at an approach that was ultimately more valuable in achieving the objectives of the research.

2.5. Participants

A total of 27 Aboriginal people participated in the research through being interviewed and/or taking part in focus groups. During the first cycle of research, the Ninti One team identified and obtained consent to conduct interviews with 20 Aboriginal people with disabilities and/or carers of people with disabilities. Interviews were conducted in settings chosen by the participants at their homes in Tennant Creek or Ali Curung or in the Home and Community Care (HACC) premises. All interviews commenced with introductions and information on the purpose of the project and the right of the individual not to participate, as well as details of confidentiality and use of the information generated. We sought permission to record the interviews.

This group of people became the core group to which we returned for in-depth and theme-based interviews in the second cycle of research. Summary descriptions of participants are as follows:

1. An elderly woman in Tennant Creek currently using a conventional wheelchair who does most daily activities on her own due to lack of services available to support her. Her main source of help is her friends and family but she would like to receive support from services to help with shopping and housing. She views her housing as not adequately equipped for people with disability.
2. A man in his fifties with a physical disability relating to diabetes. He lives on a town camp in Tennant Creek, sharing with his brother-in-law. He does not currently receive much support from services but has some help from his daughter and spends a lot of time at HACC. He uses a conventional wheelchair.
3. A women in her fifties who relies on the Julalikari Homemakers service for shopping and meals and spends most time watching television. She is very frail but able to walk and not a wheelchair user. She may have problems with mental health. Anyinginyi Health Aboriginal Corporation occasionally provides support with accessing medication. Her granddaughter is the sole carer who washes and cooks for her. They live in Tennant Creek.
4. A male in his late thirties living in a town camp in Tennant Creek and who uses crutches. He receives some support from services with shopping but would like more assistance with day-to-day management. He misses breakfast sometimes as no one is able to help him prepare food. Does not spend much time doing activities but is interested in tribal work (such as making a boomerang) and going out bush if services provided opportunities to do this. He wants a prosthetic leg to be able to be involved in more activities.
5. A male respondent who cares for his partner (both aged in their fifties) and receives payment from Centrelink. Live in housing commission property in Tennant Creek. He would like support with clearing the yard and house maintenance and wants better housing conditions. He believes that Homemakers meal service is too expensive and he does not feel other organisations provide good services.
6. A man in his fifties using a wheelchair and suffering multiple disabilities. He lives in a housing commission property in Tennant Creek. He is receiving meals from Pulkapulka Kari Nursing Home and visits daily. He has a wife and extended family to support him with everything else, but both need help with cleaning the yard. The house is not well equipped for people with disabilities and he wants railings and an extended paved driveway so he can more easily enter the house.
7. A male in his late forties in Tennant Creek who attends HACC daily and uses a motorised scooter received from NDIS. He is conscious of maintaining his health through avoiding poor food, alcohol and smoking. The family provide most support with cleaning and managing day-to-day self-care. He receives meals from Homemakers. He undergoes treatment in Alice Springs but it is too far and

would rather have services closer. He would like to go out bush but there are problems with transport and cost.

8. A daughter who is a paid carer for her mother with a disability, who is in her sixties. The mother is happy to receive most support from family as they like to be in their home and close to family. Homemakers provides some meals however the daughter would like Homemakers to provide more activities in the day. The respondent is able to move around without a wheelchair but the house is not equipped with enough railings to support the respondent with her disability. They live on a town camp in Tennant Creek.
9. A daughter who cares for her mother with a disability, who is in her sixties. They live in a town camp in Tennant Creek. Homemakers provides meals and looks after her in the day which acts as a respite for her daughter. Would like Homemakers to provide activities in the day. Family sometimes take respondent with disability out hunting.
10. A male respondent in his sixties who lives in Tennant Creek. His main concern is the current condition of his house. He does most things on his own and accesses Homemakers occasionally. The respondent does not have family support.
11. A female respondent with a disability who has a husband to support her. Both are in their fifties and live in Ali Curung. Many of the local kids help clean the house and the yard. The couple also receives visits and support from multiple family members. The couple uses few services and would like more support with cleaning the yard and house maintenance. They formerly visited bush locations regularly for purposes of spending time on country but this is now restricted due to disability and dialysis commitments.
12. A woman in her forties living in Ali Curung caring for her son who receives medical treatment in Alice Springs. They miss many appointments in Alice Springs and wish to move to Alice Springs to be closer to the services which her son needs. The woman is waiting for housing availability to open up.
13. A woman in her forties living in Ali Curung with family members and children. She receives meals from Homemakers and most of her support from her daughter. She would like help with cleaning and construction of railings outside the house. The woman is interested in going out hunting on the weekend if services provided this opportunity.
14. A woman in her forties who has diabetes, is reasonably mobile and lives in a house in Ali Curung with other family members. She receives meals from Homemakers and has a husband to support her with most day-to-day care. She is interested in working part time with school kids in school. She would like to go out hunting.
15. A woman in her sixties who lives with her son and grandchildren in Ali Curung. She receives all support from family and wishes it to stay this way as she likes to be around family.

16. A mother in her twenties who cares for young son. She is living in an overcrowded house where some beds are outside as they are waiting for a house to become available for them. The young boy needs medical treatment in Alice Springs and uses the Centre Bush Bus, a privately-operated remote transport service, to travel there and back. The family lives in Ali Curung and would rather stay there with family and be able to access treatment on their traditional country, despite needing to visit Alice Springs for treatment.
17. Three female family members and carers who provide most of the support for a woman in her thirties living in Ali Curung who is hearing-impaired and needs constant care. Her family believe services should provide her with activities to do throughout the day. The woman would like services to help with disability with communication skills, especially through sign language. She is interested in working at a school.
18. A male in his sixties with a motorised scooter who accesses services from Homemakers which provides him with meals and help with cleaning. He lives with his sons in Ali Curung and they also provide care and support. He would like to have access to medical equipment to help with mobility.
19. A woman in her late forties who lives with her daughter in Ali Curung. She is reasonably mobile using a walking frame and is able to walk short distances around the community. She would like a better equipped house with side rails in the bathroom. Anyinginyi provides medication and medical equipment.
20. A male living in Tennant Creek who receives support from Homemakers which helps him clean and supports him with shopping.

Through convening the focus groups in the second cycle, we attracted an additional seven people, mainly carers, to be participants in the research. Some were carers of people in the first group of twenty participants. Others were simply known to the team or referred to us as individuals who might be interested in participating. We have not collected summaries of these seven people as they are group participants and not subject to in-depth individual interview. The remaining five participants in the focus groups had been interviewed during the first cycle of the research.

3.0. Themes defined through collection of data

The research generated a large amount of information, some of which we recorded to audio files and later transcribed and other content we recorded directly in written form. All this material is relevant to the objectives of the research. To present it in an orderly and accessible way, we have grouped the material under themes. The content for each theme is interspersed with quotations from interviews, anecdotes, case studies and examples drawn from the participants as a means of illustrating and strengthening each thematic analysis.

3.1. Arrangements for individual care and support

Every person we spoke with receives support from family and friends. The support they receive is practical in nature. It includes help in travel (for example, to appointments in Alice Springs), to maintain their house and yard (such as cleaning) or to move locally within the region for shopping or to visit services. Although a number of the group are quite self-reliant, everyone identified important assistance they receive from family members and friends on a regular and frequent basis.

The first case study below is a good introduction to the everyday challenges for a person in Tennant Creek set against a background and history of pride in their previous active working life.

Case study 1: Getting around town

This story was shared by a man in his fifties living in Tennant Creek.

‘My leg gives me trouble. It clicks every time I try to do something. One time I fell on the bus and landed on the floor. I haven’t talked to the doctor about this. There’s nobody to push me and take me to the hospital, or I would go. It has been this way a long time.

I really need a motorised wheelchair and need someone to help me with this. I live on my own in my own place. It is a house at Mulga Camp and my brother-in-law lives there with me. A big problem is that there is no path to the front door, so it gets muddy when it rains and hard to get in the house.

Every pension day I get someone to give me a lift to the butcher’s shop to get a feed. I get a Centrepay deduction for meat but I have to pick it up. (*Note by researcher: The arrangement is for Centrepay to remit part of his pension to the butcher each week*). Sometimes they give me extra. If I can’t get there, I cry. If I can’t go, they keep the amount for the next week. If I don’t pick it up, I have no fresh meat and next door mob have to help me out, which is a shame job for me. Otherwise, my daughter cooks or I do it myself. My daughter cooks for supper and brekkie because she is working.

Case study 1(cont.): Getting around town

Sometimes I get a feed from HACC, which lasts me, but they don't take me anywhere. If they are in a good mood, they take me somewhere. I only come to the shop sometimes. I like to see my friend when he is here at HACC and I want to get a motorised chair like him. I don't know how to get one. I heard that you can get them across the road from Centrelink.

I used to work a long time at Julalikari before I became disabled. I used to be happy. I worked out on stations too. The biggest change for me was getting sick, which was about four years ago. I like to be active. I would like to work, to do something that gets me moving. My leg and back are bad. The kind of work I could do is cutting grass, a bit at a time. Before I got sick, I worked all the time. Then I had to stop and spent most time at home. So my life has been home, HACC and renal since then.

Nobody else talks to me about my care. My daughter helps me but she is not paid. She cooks, washes clothes but not personal things like going to the toilet. She works at the school and so cannot help me during the day.

I need help with shopping, walking so my leg can heal, going to the hospital. I could use the gym at Anyinginyi if someone helped me (*Note by researcher: Anyinginyi is sometimes called Congress by local people, referring to part of an earlier name for the organisation that is no longer formally used*). In the last four years, there haven't been any changes in my situation. I used to drive and I can still do it but I lost my licence due to an offence.

When I got sick, Congress helped me with medicine. Now I go to dialysis and they pick me up and bring me back. Tuesdays and Thursdays I come to HACC. It is closed at weekends so I stay home. I could do a lot of things. I see some people still working, driving and moving around even if they have dialysis, so I could do that too.

Most care for me comes from my daughter, nobody else. There's nobody to call to take me places. Sometimes I have no money for taxis. The Two-Dollar Bus is too expensive and they leave you places, so you can't get back easily'.

(Note by researcher: The Two-Dollar Bus is a colloquial name. The fare is, in fact, \$4 per trip within Tennant Creek).

Almost all participants in the research are also supported by existing organisations, especially HACC. Some people make only limited use of these services, relying more on family members. In fact, people who consider themselves self-reliant or have support from their family demonstrate great pride in achieving a way of life they consider to be a good one under the circumstances. This also applies to carers. The passages below come from both people with disabilities and carers.

"I am happy with the help and care I get. PPK helps me, which is the Old Timers. It is in Peko Road, near where I live. They help me with showering in the morning as my wife can't help me because of my shoulder. They give me breakfast and lunch and a feed in the afternoon too. Sometimes we ride in the bus. Last time, we went to Moffat, which is a picnic place past the dam. Or we go for a barbecue. I don't use other services."

“I am 31 years old, I have five kids and I don’t drink. I have been looking after my dad since he has been sick. I learned how to look after old people a long time ago and like to be around them, show respect and to learn from them. I cook for my dad. His sons are away a lot. I am not really a carer but I do look after him. We walk around mostly. We don’t have cars. We carry our shopping. We go shopping with my dad in his wheelchair and the kids come too.”

“We don’t receive other care. We find a way to get things done. We have a lot of nieces and nephews that come around. Some help us when they visit. They might grab a rake and clean up, for example. It is an ongoing situation that doesn’t change much. As for cooking, the stove is too high for me, so my partner sometimes does it. When the girls are here, they do the cooking. We manage our food from day-to-day.”

These attitudes contrast markedly with people who are clearly not doing well and are struggling to cope. One man in his thirties, who lives on a town camp a few hundred metres from the new NDIA offices, is plainly finding his situation very difficult. Unable to articulate his views clearly to the research team, he moves around on crutches, would like to be considered for a prosthetic leg and appears to be lacking much that would improve the quality of his life. As he describes below, with the help of his mother:

“I feel happy now, living in Tennant Creek. I would like to talk more to the doctor, but need some help with that. I would like to get a prosthetic leg but it seems really slow. I don’t know what happened and I don’t know what to do. A leg would be better than crutches so I can walk around better. Getting a feed is difficult because I can’t stand and cook.”

“His mother says she sometimes goes out bush and to meetings. He stays at home and it is difficult for him to look after himself. There are no other family members who can help him. He gets shaky and takes medicine for that.”

Other individuals face similar problems in their day-to-day lives:

“My wife doesn’t like being on her own, especially as some of the family are drinkers. Some of them can’t help her.”

“My partner’s back is bad and I have to lift him up. The bed is not good for him. He needs something to help him get up, like a railing. My boys help me pull him up. I need to talk to the doctor for help.”

“My wife can’t get through the doorway sometimes and needs a better way to get through.”

“My place needs improving. The bath tub is slippery. It is hard to my partner to get in and out and I can’t help him because I can’t lift easily.”

We heard many more comments similar to those above and that related to physical obstacles to mobility, mainly around the home.

As might be expected with any group of people with diverse backgrounds, interests and circumstances, the care arrangements for individuals are equally diverse. Topics of common interest are housing conditions (which feature again later in this report), mobility and access to meals.

Apart from those small number of people who are entirely cared for by their family, Aboriginal people with disabilities tend to balance care and support from family and friends with that available from local agencies in order to achieve what they consider to be the best mix for them. This subject is discussed further in the next section.

3.2. Balance of care provided by agencies compared with family and friends

All participants described most support as coming from their family. Almost everyone described using services provided by local organisations, but mostly for a specific purpose. These included support from, for example, the HACC centre, Homemakers, Congress or Stronger Women for drop-in services, meals and help in their homes. Practical helpers from the prison were also mentioned.

Most participants pointed to family support as being best for them because it comes from people they know and fits around their preferred routine. Practical devices and modifications to their houses were rated as important by most people. Others liked to have a manageable routine with assistance from family or services when they needed it. Case Study 2 shows how one person is blending family help with limited use of services plus his own goals to achieve a way of life he and his wife describe as a reasonable one under the circumstances of his disability.

Case Study 2: 'I look after myself...'

This story was shared by a man in his fifties living in Tennant Creek.

'My life changed in 1989. I used to go to boarding school in Alice Springs at Yirara College from 1977. I got diabetes, which affected my foot. I used to drink and smoke as a young fella. I went to hospital and he told me to stop, so I did.

In 2003 or 2004 I lost my leg. The reason I lost my leg was cancer in my foot. Sometimes I am short of breath. I have a motorised scooter now, since about two months ago. NDIS helped me this year. Before this, I had a wheelchair. I used to get lifts sometimes from HACC. Now I can get around and I live some way from here. Now I just get up and go and the scooter has a place on it to carry shopping.

My son and my partner help me, along with HACC staff. They take me shopping. I come to HACC every morning and get a shower and wash clothes. I like coming here to be with mates. If not, I sleep during the day. I can shower at home but I like it here. I go to Alice Springs on the Bush Bus to see the doctor. It gets me there a sensible time. The hospital pays for the bus.

The main positive change in my life would be to get more exercise. If I could get help to do training, that would be good, but it doesn't happen in Tennant Creek. Trainers come from Alice and there is equipment at the hospital. They let me know when they are here, through the people at renal. If I could train more, I might be able to walk more and do more on my own and to get stronger.

I would like to lose weight too. That would help me to be ready for a kidney transplant, which is what the doctor told me. Sometimes the food I eat is not healthy. I have lost a bit of weight and the food is healthy at HACC. But I put weight on at the weekend. I try to drink plenty of water.

Most care for me over the years has been from my partner and sometimes my son. They push me in the chair or help me in the shower. Sometimes I go without help at home, but not much. Other family help me and HACC also visit me sometimes and do shopping. NDIS will help me in the future.

The biggest changes in my life are the scooter and coming to HACC. I look after myself and haven't had a drink or smoke for 5-10 years. My son and daughter smoke and drink, but I don't go to family parties to stay away from it.'

The provision of meals was mentioned by some participants as being important to them. Some referred to general support from HACC, while others appreciated help with looking after their house and yard or garden.

A desire to be more active and to do some kind of work featured in conversations with a number of people we met. Case Study 1 is one example, as are the comments below from a couple who effectively look after each other.

"We can't have a full-time job now. We would want to work if possible, like for two days; Tuesday and Thursday when we don't have to go to dialysis. It would affect our pension. I could work for night patrol, for example. We have had experience, when I worked for CAAMA and at the hospital

(where I earned \$700), in working part time and managing it with my pension.”

In some cases, as the example above, there was uncertainty about whether they could work and still receive a pension. Others simply wanted to keep their bodies as active as possible:

“I am trying to get my relative to train to walk with a frame so she can be more mobile. Really most special help like this comes from Alice Springs rather than in Tennant Creek.”

“For me, I walk everywhere for exercise reasons. I go up Battery Hill.”

Case Studies 2 and 3 make similar points about people being aware of the need for them to keep as active as possible and to be aware of the kinds of food they are consuming and its effect on their health.

3.3. Disability and culture

Although in our experience not a regret confined to people with disabilities, a sense of not being able to practise culture is important for the Aboriginal people who participated in this research in the Barkly Region. In talking about the subject, they often refer to a strong desire to go out bush more often and refer to the needs of older people, as illustrated by the passages and quotations below

“Before we used to spend a lot of time out bush, hunting and camping. We used to go whenever we wanted but we can’t do that now. Renal is three times per week. We have to let people know so they can look for us if needed. We can’t spend time on country now. My home community is 50km away. Renal wears you out too.”

“If we go hunting, we need 2-3 cars. We have a lunch break out there. We need to plan it. We miss going bush. It is important to us because we grew up that way, lighting a big fire instead of a 44-gallon drum in our yard, looking around with no streetlamps and just the moon. It is part of our lifestyle.”

“I like to go bush. Taking the person we are caring for to cook kangaroo tail is good. Just going for the day and coming back in the afternoon is good for old people as it goes back to what they used to do. Town is a bit jammed with traffic and drinks and everything. Old people feel lighter out bush. They feel free because it is their home. They find it boring in town. Digging and eating bush potatoes is best for them.”

“The problem now is that we don’t have vehicles. HACC used to take them but it has a new manager now and they don’t go any more. Going out to Phillip Creek Station is good because that’s where they are from. But dialysis makes it hard unless we time it properly.”

“Being out bush brings out a lot of stories but in town you are mixed up and disturbed. In town you see family drinking and it makes you want to

drink. Out bush you can talk to other people easily. Eating a goanna and cooking damper is good too.”

“People feel sad if they can’t go out bush. Their mums and dads taught them how to live on the land and they want to show the kids and sit around the campfire. Getting up early and cooking is good for them. Talking at night happens.”

“Some people talk about going back to their homelands but there are no renal machines out bush.”

“A bus to take people out would be good. Not sure if people would pay for that. I would love to do it but nowadays everything costs money.”

“I can’t walk any more. I would like to teach the young girls but I can’t get out bush.”

“As a senior man in the community, I am expected to go out bush, but can’t because I have to look after my wife. For me, this part is hard because I can’t do both.”

“The main cultural side of things is that we have commitments at the culture ground. In town, we can do them, but away from town is harder.”

“I am the main man at some meetings and I can’t even go. My family can’t really cover for me.”

Some people are finding ways to meet their cultural needs and obligations:

“If we have to go to CLC (Central Land Council), they are flexible to allow us to attend. They have meetings in town sometimes, as well as out bush.”

“In my case, my husband goes to HACC for a while and can even stay there sometimes, so I get a bit of a break and I can go out bush. There are other men at HACC, which is good for him.”

People’s connection to their culture is always more complex than can be explained in words. From discussions we conducted, set against Ninti One’s wider knowledge of cultural practice, we discern four key points:

1. People feel better when they can spend time out of town and on their traditional country. There are many reasons, most of which are intensely personal and spiritual in nature.
2. The notion of ‘feeling better’ has a mental health connotation. In other words, people are less sad, they feel more optimistic and replenished and more able to cope with everyday struggles. In other words, for people who may be vulnerable to mental health conditions such as depression, cultural expression has a therapeutic value.

3. Physical disability is not seen as complete barrier to bush trips because people are accustomed to getting around the place they live and often the locations they want to visit can be close to Tennant Creek or Ali Curung. A bigger constraint is cost and the availability of a vehicle.
4. There was no sense from carers or people with disabilities that stigma or exclusion is part of the problem for people wishing to participate in cultural activities. The pace of life in the Barkly Region is slower than large urban centres and so pressure that comes from other people's schedules is lower.

3.4. Stories and insights from carers

“What makes me happy is us doing things together like shopping, using the trolley. Sometimes he hangs on to me but we do it. He might buy something for himself.”

The quotation above is from the wife of the man described in Case Study 2. Carers are not necessarily people in whom others take much interest and so they rarely get the opportunity to talk about their experiences and their knowledge. As might be expected, many carers experience a tension between wanting to support their family member as much as possible but also needing respite and support themselves in many cases. Some people use existing services in the Region to achieve a balance that works for them, while others are often desperately in need of a break from the demands of being a carer.

The quotations below are from a focus group with carers in which they discussed their experiences. Many people remarked on how they became a carer.

“Most of us grew up on the black soil tablelands. I first looked after my youngfella from when he was 10. I used to go to the school with him. He had a kidney problem at around 20. After a while, the doctors couldn't do much more for him. The hospital called me up in 2004 and he went to Adelaide for a transplant as soon as a kidney was available. I looked after him when I was working. Then I stopped work to be with him. We travel to Alice and Darwin sometimes for treatment.”

“I learned to be a carer since I was 18. I learned a lot about it. Nobody taught me. I looked after three old people. When people have disabilities and go to renal it is very hard.”

“As a couple, we used to work. Then we got sick. I used to be a singer. We used to take the younger people and teach them. When my partner got sick, I just stopped to help her. Where we are staying, our daughter-in-law could look after us.” (At this point, someone else said ‘She was a healthy old lady and one of the best in Tennant Creek’. ‘She was a happy and hard-working old lady, walking around and doing stuff’).

The conversation moved on to practical work carers need to do and some people take great pride in the standards they set:

“You have to keep the room where he stays very clean, spotless. It is a lot of work. In my thirties I am better now at doing this work. I get up at 4.30am every day. If the power goes off I have to make sure he can get to hospital. One time the nurse said ‘Are you his partner?’ I said ‘No, I’m his fourth daughter’.”

“I look after my mum by cooking, cleaning and shopping. We don’t have a washing machine. We have some contact with agencies like the women’s centre. We live in Blackmore. “

“We have a house but we prefer to sleep outside. The shower is a slippery one.”

“I love caring for my partner as I like doing something for him. We go for walks together. One time he cooked damper and that was a big surprise. I didn’t know you could cook, I said. I kept pinching him.”

Some carers are interested in getting greater opportunities to rest and fresh themselves:

“There should be respite for carers, like the PPK place. I have details of the National Respite for Carers Program and I want to contact them because they said they would help me go somewhere for a break. I look after my wife and I get an allowance of \$50 to care for her, that’s all. I pay \$150 for rent.”

“When I am sick myself, nobody looks after me. I live in a unit and look after myself. My daughter does not help me. I get no help from family or agencies in town. Nothing.”

“Life is quite hard for a single mum like me, as well as caring for old people. They depend on me. I am nominee for my dad at Centrelink. A lot of paperwork is needed for Centrelink.”

Other carers have arrangements with the people for whom they care and local centres to provide support most days on a drop-in basis:

“I look after my stepson and he goes to day centre in Caroline St, which is called PPK. I don’t get a carer’s payment. I work with disability services and homemakers too. I like helping people with disability, especially old people.”

“I am doing the care work on my own because nobody helps me. I do a lot of work cleaning, washing, getting her ready for renal. I don’t get much rest. Other family members in the house don’t do anything. They see it as my job.”

Carers who we interviewed described an important part of their role as ‘looking out’ for the person they were caring for. This meant that they were concerned for the safety of the other person and in making sure other people understood their situation

and their disability. One carer said boredom is sometimes a problem they try to help overcome.

Many more comments were made by carers during the focus groups and interviews, but here we have concentrated on the key insights gained, especially as some observations were variations on an earlier topic. Overall, discussions with carers present three overall sets of impressions:

- First, they are often very experienced and have developed ways to do their work in a way that suits the person they are caring for and themselves. These arrangements extend to all aspects of daily and weekly routines. Disability often brings a necessary structure to people's lives that they didn't necessarily have before they were disabled and when activities did not have to be planned in the same way.
- Second, the individuals with other family members close by and visiting on a regular basis benefit greatly from the extra help. People mentioned having sons, daughters, nieces, nephews and others who come by to help clean, cook, rake the yard, move heavy items and a range of other everyday support. Arguably, knowing they have a network of people available to help them is the greatest source of comfort for carers. As one couple said

“Our children care for us. They don't get a carer's allowance but they help us as family members, including looking after the house. They bring groceries for us.”
- Third, carers are often resigned to situations that are not optimal for them. The best example is housing maintenance, which frustrates many people and yet they cannot manage to address, despite regular requests to the relevant local agencies. Another is help with mobility (through modifications to their homes or access to scooters), respite support and often advice that they can understand easily. As one person said “It is hard for old people if they go into Centrelink and they get hit with a word they don't know. They need someone to interpret for them”.

Our questions about payment of carer's pensions led us to understand that a significant number of carers do receive a pension while a similar number do not. For the second group, they already receive other benefits (such as Newstart) and so are not seeking other payments or believe they would not qualify. A small number are uncertain about whether they should be applying for other benefits. At least one person said he used to receive a carer's pension but was taken off it when his circumstances changed, although he is still a full-time carer.

3.5. Challenges for people with disabilities and their carers

Some of the research was conducted during a period of public debate and controversy in Tennant Creek on the subject of housing maintenance. During one of our visits, a protest march took place through the town to complain about the performance of Julalikari Aboriginal Corporation in maintaining properties in the town and this was reported in local and Territory media. In response, Julalikari has pointed to high rental arrears as being a source of underfunding for their work, as well as delays with contractors.

Regardless of the rights and wrongs of the debate, housing was described most often to researchers as the major problem people face, whether managed by Julalikari or Territory Housing.

“The driveway is not finished yet and gets difficult in the wet. Someone called Paul is looking into improvements for me like the bathroom and driveway. We want the screen door fixed too because we had a snake in the house and I couldn’t escape. This house was never renovated properly when they put us in here. For example, the lighting is not finished. If you can’t see, there might be a snake out the back and could be dangerous.”

“A big problem for me is that the house is old and not renovated. The door handles, shower and other parts are not safe for the youngfella I am looking after.”

“We asked Julalikari to cut the grass and it cost \$300. We have to pay for cracker dust for the yard. If we need anything done, like cutting the trees in the yard, we have to wait too long. They say ‘you are on a list’. For a crow’s nest, it costs \$100. We are better to do it ourselves.”

“Sometimes I have asked Julalikari to fix things. They write it down but nothing happens.”

“Same happens for me. It is not good for the old people. What’s the matter with this mob that they can’t do it?”

“We live at Mulga Camp. We asked for renovation but nothing happens. We had a stove for five years and only one plate works. A switch on the wall doesn’t work and the same with the smoke alarm. It doesn’t get fixed.”

“I like to lock the door when I go out but the handle is broken. We are paying rent, like \$250-280 a fortnight, but we don’t get a service.”

We received other comments along these lines. The importance of this subject from the perspective of people with disabilities and their carers is that the prospects of achieving mobility-specific improvements to their properties seem remote when even basic repairs are so difficult.

A number of people mentioned the value of simple modifications in the home, like rails in the bathroom and shower. While most participants already have these improvements in their homes, some have not been able to secure the support they need. In a small number of cases, the individuals had not requested improvements from local services. As a result, the observations made by respondents were a mixed bag of positive and negative remarks:

“Joseph once came to visit us from Alice. He is an African disability person and checked my wheelchair. I want to get a scooter. Sometimes I fall out of the wheelchair when it topples.”

“Our house is well set up for my partner. We live on a town camp. We even have a chair for my partner to sit in the shower.”

“Ramps are good in some places and getting into and out of most shops is easy enough.”

“My place needs improving. The bath tub is slippery. It is hard to my partner to get in and out and I can't help him because I can't lift easily.”

“I have problems in the condition of the house, like a leaky toilet and a hole in the wall. Sometimes they do inspections and nothing happens. I have been there twelve years. I have a broken window, door I can't lift and so we have to enter through the other door.”

Around half the participants have specific aims or needs on which they place particular importance. Several participants described personal goals they would like to achieve, such as joining a particular training course, learning a skill (like computer use), securing a driving licence or taking up an interest like painting or crafts like bead work. One person expressed a strong desire to teach children about culture and another was interested in teaching children to cook damper. Although most were unable to work, at least two people explained how they would like to work again, given the opportunity.

“I am interested in painting and computers. I have brain and memory problems and so sometimes forget. Nothing has happened about that yet. In PPK they have tablet computers that I might be able to use. I have a laptop but my daughter uses it all the time. I use it to watch movies sometimes.”

“Sometimes I think about making a boomerang for myself. I want to learn.”

In most cases, participants did not have many broad suggestions to make. Some individuals talked about relatively modest needs they have, such as installation of ramps or handrails, improvements in their car port design, cleaning or house repairs. One person would like to have access to a motorised wheelchair. Another individual complained about the cost of the food they were receiving and their desire to move out to a different house, although this was part of their general unhappiness about their house not being clean and visitors not looking after it properly.

Several people mentioned the trips they make to Alice Springs for health appointments and a small number liked going there for shopping and to see other people they know. A small number of participants mentioned that travelling to Alice Springs for some services presented them with a difficulty. One person said they miss many appointments in Alice Springs and wish to move there to be closer to the services they need. They are waiting for housing availability to open up.

We found that most people had definitely heard about the National Disability Insurance Scheme (NDIS) although did not know what it had to offer them. Others had heard nothing about NDIS and expressed interest in learning more. We left booklets, information sheets and contact cards with many people.

The case study below is a good illustration of a couple with health conditions that have led to them being disabled and who look after each other, following a period when they were healthy and working. The use few services, have support from their three children and have aims to improve their situation.

Case study 3: Learning to do things that were easy before

This story was provided by a couple in their fifties living in a town camp in Tennant Creek.

‘The biggest change for us was went we got sick and had to learn to do things that were easy before. Like walking around. I used to drive a bus and had a blackout when I was driving. The doctor doesn’t let me drive any more. We stay home most of the time. We get visitors. Our kids help us out.

(Woman) I would like to do a course but difficult as I am not well. I get short of breath even when I walk. I need help to reduce my weight and the clinic has talked to me about it. The gym at Anyinginyi is a place I go sometimes.

(Man) I still get to go out bush at weekends sometimes, which is what I like to do. If I feel sick, I get frightened and come back. I was worried I was going to die one time. I have fallen over before in the yard. Out bush, I visit family and stay at the outstation. Our children care for us. We have three boys; 22, 17 and 12. They don’t get a carer’s allowance but they help us as family members, including looking after the house. They bring groceries for us. We feel happy with things.

To give some of the history, we met in Tennant Creek in the nineties. (Woman) I lived on a town camp with my mum and dad. We both lived there, in fact. When we had children, we still lived there. But when I got sick, which is this one we are in now. The doctor helped us to get it.

Before we got sick we were working. One of us was at IAD in Alice and travelled to run courses in Darwin and other places. She was on CDEP too. I was the same. My wife went to bush school because I lived remote. I went to Yirara College after that and then to school in Elliot. I worked on a station when I was 16-17.

A few years ago, we had to be admitted to ICU for two days but we recovered’.

For a small number of people, visiting Alice Springs for treatment and consultations is important. The case of a woman caring for her son in Ali Curung is instructive:

“I live with my Mum and Dad in Ali Curung. They give me support because I have three children and look after them on my own. I am in my early thirties. My youngest son has a disability and I am his carer.

I feel safer if I am near a hospital and my son needs medical treatment sometimes. My youngest was in intensive care for a while last year. I want to move to Alice Springs so I can be near the hospital and my children can have space to grow up. I am on the waiting list for a place in Alice Springs. Our house in Ali Curung is overcrowded.

In Alice, I had good support when my son was sick. He was in the hospital for two months.”

The case study below focuses on the demands of gaining access to services over the large distances that exist in the Barkly Region and the Northern Territory. It illustrates a willingness we heard from several people to move to locations within the Territory that would enable them to gain better access to specific services. This point was not made as a criticism of existing services in the Barkly but more as an acceptance that the individuals would feel safer and more comfortable if they didn't have to travel to places like Alice Springs on a regular basis, even if infrequent.

Case study 4: Moving closer to services

I am 62 years old. I used to live in Murray Downs, on the Davenport Highway in the NT, then I moved to Ali Curung in 2000 due to illness. I had breast cancer. I live in a three-bedroomed house with my daughter, who is a paid carer (receives a carer's pension). When my daughter is not around, I spend time across the road at my sister's house, although I like to do as much as I can by myself. I like to walk around slowly and keep my body moving, which I am sure is better for me. I have a walking frame.

I get assistance with breakfast and lunch brought by Homemakers. I struggle to manage in the house sometimes. The shower floor is slippery. I need a ramp to my front door because the floor is much higher than the ground and I don't like to strain to reach it. I need rails in the bathroom because I worry about falling.

I go to Alice a lot to see the bone specialist. I have arthritis. I am trying to stop these things getting on top of me. Things changed for me when I got sick and needed to be closer to the clinic, which is why I moved to Ali Curung from Murray Downs. I am happy with the care I receive and often think about moving to Tennant Creek for a change of scenery. I have family there.

I would like to have a shed to lock up my mop and buckets, which go missing. I would really like to have a lawn too. I need help to clean the house from time-to-time. Cleaning products and food are expensive in Ali Curung and I would like more money so I can afford what I need. I need help to clean the house when my daughter goes away. I like her to have a break. My sister helps me during those periods.

In summary, the challenges described to us relate to two areas of the lives of people with disabilities; the quality of housing (mainly unresolved problems), the need for mobility-specific improvements and unfulfilled wishes to pursue a particular aim. Smaller numbers of people, as described in earlier sections and case studies, described their need for a scooter or mobility aid.

We also noted that no comments were made by respondents that implied problems with specific (non-housing) agencies including the drop-in centres or Centrelink. The same applies to commercial and other businesses in each community, none of which attracted any comments from the people we interviewed.

3.6. Aspirations

“The doctor told us to cut down on fatty foods. We want to eat more bushfoods. We use to eat bush tucker all the time, like kangaroo.”

The quotation above comes from one person in a couple we interviewed. It shows the connection that exists for some people between culture and healthier lifestyles. Going out bush, eating bush tucker and being active represents both an improvement to people’s health and cultural lives. The case study below continues this theme and comes from a women who sees benefits in a number of activities in which she is involved.

Case study 5: Hunting, painting and working

I am 52 years old and I live in Ali Curung with my husband, nephew and his wife. I am on dialysis and my husband cares for me by carrying me, cooking and cleaning. He receives a carer’s pension. We exercise together.

I lived in Alice from 2001 and moved back to Ali Curung in November 2014. I used to drink a lot but was advised by doctors to stop. This was the main change in my life. I feel good and happy. My partner also stopped drinking and supports me. We go hunting for bushfoods, which makes us happy. Our relationship is a strong one. I receive meals on wheels; breakfast and lunch. I enjoy painting stories I have been told about by my family.

In the house, we share expenses. My brother helps by cleaning the yard. I have good support and when I have been to Alice he comes in and cleans up the yard, which is good for when I return. Sometimes my grandchildren and children travel to see me from Alice and so the yard is clean for them to play in when they arrive.

I like being back in Ali Curung, connected to family again. I am committed to getting back to work. I am waiting for a transplant. I used to work at the store, office, clinic and school. I have skills I can use.

I enjoy learning about computers and could do a course. I am back at church now and my husband and I would like to teach bible stories to families who would like to learn. My husband was trained by a doctor to help assist my wife with the dialysis machine.

In conclusion, since aspirations have been touched on in other sections, this one includes other perspectives that have not been featured earlier. Although there are notable examples in Ali Curung and Tennant Creek of people with disabilities pursuing personal and individual health, cultural and work goals, our overall assessment is that a far larger number of people have aspirations that are not fulfilled. In most of these cases, they appear not to know where to begin to make positive changes happen in their lives.

4.0. Conclusion

The purpose of this report is to describe the process and results produced by Ninti One through research to help determine effective support arrangements for Aboriginal people with disabilities living in the Barkly Region of the Northern Territory.

In conclusion, we provide a summary of the findings of the research against the two objectives of the work, which incorporate the four supporting themes described in the introduction to this report.

Objective 1: How care and support is currently provided to people with disabilities and the different roles played by families and services.

Individuals and families manage support from family members and agencies in a way that they believe best suits their needs. Relatives, especially partners, are a major source of care for almost everyone. Some people can count on occasional visits from younger family members to help with particular tasks around the home, while others receive close to full-time care from their partners. On the other hand, others are more isolated and dependent on transport and drop-in services. There exists a reasonably even balance among those we met of people who consider themselves 'paid' carers receiving an allowance and those who are not.

Although participants, whether carers or people with disabilities, are usually entirely able to describe the services they use and how they use them, the research raises doubts as to whether people really have the information they need to make optimal choices. For example, some people with disabilities and who spend a lot of time together could not (or were unwilling to) explain why one of them had access to a motorised scooter while another did not. Similarly, where individuals are regular users of a particular service, it was not apparent that they had considered other options and made an informed choice. Location and proximity are often important factors in choices given the challenges for some people of getting around their town or community, but this does not mean that they are making the best long-term choices.

A noticeable trend in the research is that people with disabilities often rely on service providers for standardised and regular support such as meals, house repairs or modifications and transport. They need family and friends for more personalised care such as helping them cook and clean, tackling specific challenges such as mobility within their home and making sure they are looking after their health and safety.

Objective 2: What people with disabilities think about the support they receive now, and what they think would improve their wellbeing if they could choose more support.

Listening to views of people living in remote places needs to be set against the reality that few people have experience of services, support and care from other parts of the Northern Territory or elsewhere in Australia. So their responses to questions on this subject are often made without a reference point or benchmark coming from their knowledge of other places. Living in remote Australia is by nature an isolating experience for people unable to travel to larger urban settlements.

With the very clear exception of housing, opinions expressed to us about current support were generally positive. People believe they are using support and care services in a way that works for them under the circumstances of remoteness, climate and resources available in the Barkly Region. Most people can describe their daily and weekly routines in a way that demonstrates a degree of satisfaction, although tempered with a desire to be more active, make trips to bush locations or accomplish more tasks around their homes. Nobody mentioned being stigmatised or denied access to services or facilities, despite the cost of transport and some amenities clearly being an obstruction for some individuals.

There are, however, notable exceptions to the picture of people coping with their disabilities that we describe above. Some people's homes are not as safe as they should be. Some individuals struggle with transport and mobility in ways that appear relatively straight forward to address. Others are isolated, especially if they have contact with few family members. Although not a topic of investigation for this project, the presence of mental health and substance abuse problems is likely.

The lack of repairs and maintenance to housing has been well-documented in the report and, as mentioned above, points to safety concerns for residents with disabilities. Examples are where lighting needs repair or connection or doors are effectively not working and blocked. Driveway access for wheelchairs is sometimes unfinished. The research took place at a time of well-publicised complaints against housing agencies in Tennant Creek, which have now reached crisis levels.

Setting aside these issues to concentrate more on the adaptation of housing to meet the needs of people with disabilities and their carers, there are shortcomings for a number of people. Simple improvements like handrails in bathrooms have not been undertaken, although it remains uncertain as to whether they have been requested by the people concerned or not. Often, our sense was that people make do with their situation rather than knowing where to request improvements or what might be possible.

The research explored the question of disability and culture, which is where a very strong connection to individual well-being emerged. Our questioning was careful not to prompt or lead to a particular set of responses, but opinions were consistent. The majority of people we approached about this subject took the view that the

opportunity to spend time in bush locations improves people's happiness, morale and satisfaction with their lives. Although some individuals manage to make trips to places special to them, most do not because of the demands of dialysis schedules, lack of transport, cost or the general effort required to do so.

Similarly, we met a significant number of people who described personal aspirations that would improve their lives. Given the number and diversity of aspirations expressed through the interviews and focus groups and the relatively few that have been realised, we consider that barriers exist to people achieving their personal goals. It is usually not easy to discuss these barriers through interviews because people are often unhappy with themselves and feel 'shame'. Our assumptions are that individuals may not be as motivated in practice as they appear to be when discussing their goals. Of course, physical disability can make the aim very difficult to achieve. Another reason could be that individuals are not adequately supported to achieve their aims though, for example, a regularly-reviewed personal plan.

The role of carers is important here. There is no doubt that some carers consider part of their role to be to advocate on behalf of their family member, making sure he or she has what they need. Achieving the basic routine of care and support is enough for most people and that branching out into more ambitious aims can be too demanding. After all, many carers are carrying a heavy workload. In addition, it could be that family members do not have the information or ability to help individuals meet their goals. Although the interviews generated few complaints about this, there is scope for considering the levels of dependence of people with disabilities on a small number of family members and whether further support could be offered to the carers. Simple challenges like having to physically support their partners is a big issue for people who are not themselves very strong, a point which leads us back to the need for better housing maintenance and the scope for technical adaptations to homes.

We conclude with some reflections on service models. Meetings with service providers were beyond the scope of the research and so our comments are not informed by their views or knowledge we have gained of current service arrangements from a provider perspective.

The cultural needs of Aboriginal people in the region are important and directly relevant to well-being. Assessing the needs of people in a way that acknowledges cultural factors would help address some of the pressures on wellbeing that exist among people with disabilities. Similarly, helping people understand the services available, the options for adapting their homes and gaining access to mobility devices would certainly assist some people we met and improve their lives dramatically. A much-needed breakthrough in the housing maintenance crisis in Tennant Creek would be another step forward.

On the subject of carers, the range and diversity of support and care provided by family members is very large. Supporting them to be effective in seeking opportunities for the people for whom they are caring would be a valuable initiative,

but again we make this comment without an insight into how this work is already being done.

We consider it worth benchmarking service and workforce arrangements in the Barkly Region against those of other locations in Australia to determine whether there is scope for improvements that would benefit individuals with disabilities in the region. This subject includes workforce training and development, access to and types of services, cross-cultural aspects of services, responsiveness of services to individual needs and service gaps.

