

Our experiences as Aboriginal carers

Findings from a 'yarning circle'
held in
Port Augusta
2015

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The project partners of this project are:

- Social Policy Research Centre (SPRC), UNSW Australia
- University of Leeds
- NSW Health
- The Department of Education, Employment and Workplace Relations
- Department for Communities and Social Inclusion (SA)
- Carers Australia Inc.
- NSW Department of Family & Community Services

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Carers SA - Port Augusta

Carers and Social Inclusion

Background information

Social inclusion focuses on participation in public sphere activities (education and paid employment), but often overlooks informal care. For Aboriginal and Torres Strait Islander people/s, social inclusion is yet to fully address some of the cultural aspects associated with care-giving.

This Australian Research Council Linkage Grant *Carers and Social Inclusion: New Frameworks, Evidence and Policy Lessons* project used a mix of approaches to deepen understanding about carers' inclusion across different aspects of life. It used this knowledge to think about 'social inclusion' in a way that acknowledges carers' participation in many aspects of life. This evidence will help inform the development of indicators and policies to foster the social inclusion of Indigenous and non-Indigenous carers.

The project aims

The project aimed to:

- Document carers' social exclusion.
- Think about social inclusion in a way that can include the lived experiences of carers.
- Provide evidence to inform policies which support carers to engage in many aspects of life.
- Develop indicators of social inclusion most relevant to carers.

This project is made up of the following themes:

- Theme 1: Re-thinking social inclusion to acknowledge informal care as both an indicator of inclusion and risk factor for exclusion.
- Theme 2: Exploring informal care and social inclusion in Aboriginal and Torres Strait Islander communities.
- Theme 3: Comparing the social inclusion of carers in Australia and England.

Exploring informal care and social inclusion in Aboriginal and Torres Strait Islander communities

The findings in this booklet are focused on the experiences of care and social inclusion for Aboriginal carers in Port Augusta, which form part of Theme 2 of the broader project.

The aim of this theme was to:

- Undertake a comparative analysis of research, policies and programs about carers and indicators of social inclusion in Indigenous

communities in Australia, New Zealand and Canada to identify theoretical frameworks and policy lessons.

- Explore the concepts, meanings, and experiences of informal care and social inclusion for Indigenous Australians in urban and regional communities.
- Develop indicators of social inclusion for Indigenous carers and identify their policy

What we did, and how we did it

The researchers at the Social Policy Research Centre (SPRC) first worked with the First Peoples Disability Network to identify communities that they were currently working with, and where there might be opportunity to provide further support to their work. Through those conversations, and on the basis of where Aboriginal carers live in South Australia, we approached carer organisations in Adelaide (Northern Carers Network (NCN)) and Port Augusta (Carers South Australia – Northern Country Carers (NCC)) to discuss the research. On advice from the SA AHREC, we also consulted with the Carers SA Aboriginal Partnership Group about the research and proposed methods.

The SPRC, UNSW Australia; Carers SA; and Aboriginal carers met a number of times in Port Augusta to discuss the research, what it might look like, carers' experiences and the findings from the research. Port August is a regional town in South Australia. It is over 300km from Adelaide via road. Most major services (such as hospitals) are located in Adelaide.

To ensure that process suited the Aboriginal carers in Port Augusta, we met three times including:

1. First visit/chat on the phone and a face-to-face meeting between SPRC and NCC about:
 - this research and what it might include (i.e. a yarning circle over lunch time or morning tea);
 - whether there was interest in your community; and
 - see if carers and service providers want to be involved.
2. Second visit (face-to-face)(the 'yarning circle'): the approach taken for the the 'yarning circle' was to give Aboriginal carers the options for how they wanted to tell their own stories. At the beginning of the 'yarning circle' carers were given the option for starting with an activity to write down their initial responses to the questions and then convene in a group to talk, or to have an open discussion. The group opted for an open discussion.
3. Third visit (face-to-face): presentation of findings to the Aboriginal carers who participated in the 'yarning circle'.

'Yarning circle'

The 'yarning circle' was an open discussion with Aboriginal carers, which allowed the carers to talk freely about their own experiences as a carer. The 'yarning circles' and the third visit was mostly mid-age and older female carers. However, male carers were also participants.

The 'yarning circle' went for one (1) hour and was guided by the following questions:

1. How did you become a carer? (did you choose to be a carer?, family obligations, love, responsibility, no-one else available or around).
2. What do you do as a carer? Can tell us about your day-to-day life as a carer?
 - a. Who do you care for?
 - b. What is your relationship to the person you care for?
 - c. How many people do you provide care for?
 - d. What are the things that matter to you as carer?
3. Do you feel that being a carer is important?
4. Do you get help?
 - a. Who helps you?
5. How has being a carer affected your life?
 - a. Do you feel that being a carer is difficult?
6. What do you get from being a carer? (What do you think is good for you about being a carer?)
 - a. Is there anything you miss out on from being a carer?
7. What things can you do/or be a part of because you're a carer?
8. Are you involved in any outside activities?
 - a. Are there any activities would you like to take part in, but can't?
9. If you can tell the government about what is important to you, and makes your life better, what would that be?

Findings

This booklet contains the findings from the 'yarning circle' with Aboriginal carers in Port Augusta. The views presented in this booklet are based on the experiences of Aboriginal carers and do not necessarily represent the views of the supporting organisations.

These findings will help inform the basis of indicators for social inclusion relevant to Aboriginal carers.

How we became carers

We became carers through a mix of wanting to care, out of obligations and responsibilities to culture and family, and limited choices, opportunities and alternatives. In some cases we took on the carer role because there was no-one else in the family who could care, no-one else wanted to do it, and we knew that someone had to provide care.

What care means for us

Caring for family members is just something that Aboriginal people 'naturally' did, or is part of our 'culture' and 'way of life' as Aboriginal people. Caring for people with disability, our old people, and people with chronic illness or long-term health needs is a part of our kinship networks and is not distinct from caring responsibilities for children and other family members, nor is it distinct from 'alternative care'.

We became carers because:

- It's part of our culture
- It's our way of life
- We are family orientated
- We found ourselves in that position
- We wanted to care
- No-one else in our family was able to do it
- We had limited choices



'How most carers came about to being a carer is because most of the time they're pushed into it because they're seen as "well, that's your family. You deal with it." And there's no one else around... Yeah they might do it out of love, you know. They see there's a family obligation. But, you know, most of the time carers are put, you know, pushed into it basically'





Recognition as a carer

We do not always recognise ourselves as 'carers.' The role we play as a carer is part of our normal role as spouses, parents, grandparents, children, sisters, brothers and friends.

When we have recognised ourselves as 'carers' this has usually occurred through a 'facilitator' or another person (e.g. a service provider, a family member, a stranger in the shop) pointing out that the relationship we have to the people we care for would be considered as a 'carer' role.

We do not always recognised ourselves as carers because it's part of our:

- Role as Aboriginal children to care for our elders
- Role as parents to care for our children
- Marriage vows to care for our spouse
- Culture to care for each other

What we do as Aboriginal carers

Absoriginal carers play a large number of roles from household chores to transport, filling in paperwork, decision-making, monitoring changes, being on-call and protecting the care-receiver.

'I care for my son...he lives on his own. I'm forever telling him...because he lives in a rental they can kick him out any time, that sort of thing. I mean he's not dirty, dirty, but he just doesn't put things away'

'She does rely on mum and dad to - to do things now because she can't. Like, they've taken her licence away. So, no, mum and dad now have to transport her if she needs to go to medical appointments or just, well basically go anywhere you know'

'When it's a family member, you don't expect them to go and apply for Centrelink because that's to get assistance. But then when the carers do go to get assistance it's the written role...and they get told "Fill in this paper in." Don't ask whether or not can you read and write. "Are you able to fill this form in?"'

Who we care for

We care for people in our families who have disabilities, chronic illness and long-term health needs, mental illness, and the elderly. This includes our children, parents, in-laws, spouses, grandchildren, and grandparents. Some of us take on the carer role for more than one person at a time, or are in carer arrangements where people are carers for each other.

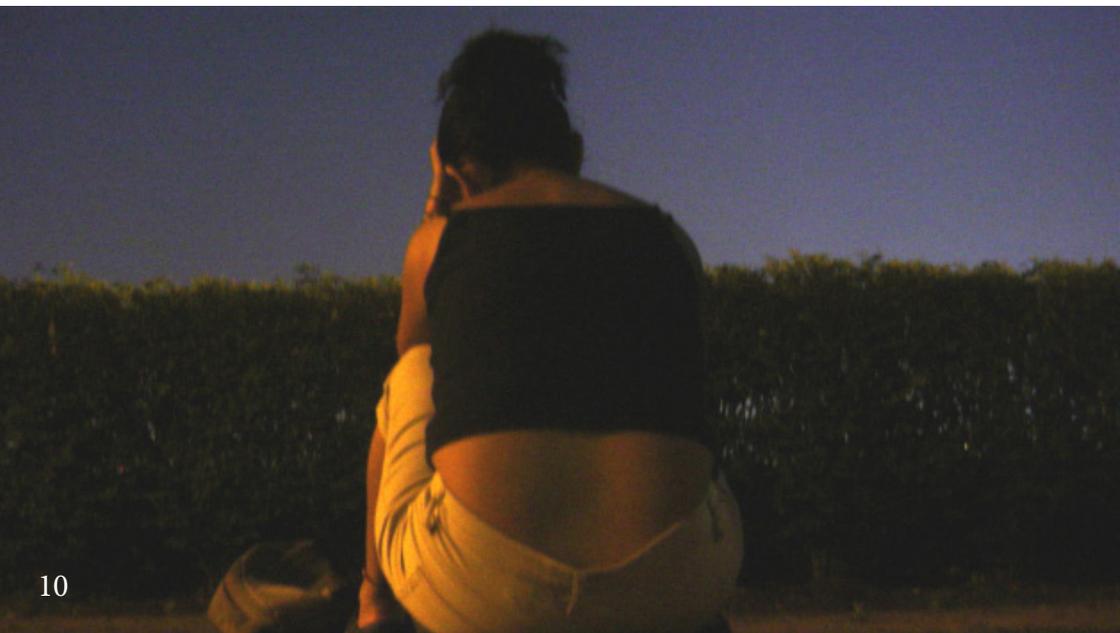
Examples of some of things we do as carers:

- Advocacy
- Decision-making
- Protect the people we care for from harrassement and abuse
- Be on-call during the night and day
- Cooking
- Bathing
- Washing clothes and dishes
- House cleaning
- Transport

ad·vis·ed·ly (ăd vīz'əd-lee), *adv.* deliberately.
ad·vise·ment (ăd viz'mənt), *n.* 1. consultation; the application of
ad·vis·er (ăd vī'zər), *n.* 1. a teacher who helps stu
2. Educ. a teacher who helps stu
of studies, etc. Also, **ad·vi·sor**,
ad·vi·so·ry (ăd vī'zərē), *adj.* having power to advise; an advise
ad·vo·ca·cy (ăd/və kə sē), *n.* ac
ad·vo·cate (v. ăd/və kāt/; active
porting, or recommending; active
-cated, -cating, *n.* —*v.t.* 1. to pl
port or urge by argument; recomm
vocated isolationism. —*n.* 2. one
cates, or espouses a cause by argum
defender (fol. by of): an advocate of
leads for or in behalf of another; inte
cot., sometimes English, and former
eads the cause of another in a court
vocātus (prop. pp.) one summoned to
al case); *r.* ME *avocat*, *t.* OF] —*adv.*
vo·ca·tion (ăd/və kā'shən), *n.* an ac
n action before itself by a superior
t. 2. Obs. advocacy.
ad·vo·ca·to·ry (ăd/və kə tərē), *adj.* func



Being an advocate for the people we care for can be difficult and time-consuming when we are faced with situations, services and individuals who do not understand what it means to be a carer and the responsibilities we have to the people we care for, or where racism exists and means that we cannot have our voices heard and accepted.



How the carer roles have affected our lives

Being an Aboriginal carer is both rewarding and challenging. We have opportunities to care for the people we love, and spend time with those we care for.

The rewards and opportunities afforded from caring

Being an Aboriginal carer is rewarding and affords us opportunities to spend time with the people we are caring for. In our carer roles we get to know the people we care for very well. We come to understand and know their feelings, goals, aspirations, dreams for their own lives.

Being an Aboriginal carer is also healing, because it gives us opportunities to spend more time with our families and to pass on and receive cultural knowledge.

The challenges of being an Aboriginal carer

Being an Aboriginal carer also has challenges. If you are receiving a carer payment there are restrictions on how much time-out you can take.

'Being a carer, too, you're only allowed so many hours away from that person. I think you're only allowed, what, four hours away...And yet when you look at if you had a doctor's appointment for yourself on some occasion there's four hours gone just there, depending on the doctor you've gone to see, you know. So there's your time gone. So don't worry about doing shopping in that four hours, you know, that week or that, you know, or anything else because your four hours has gone'

For young carers, caring responsibilities can impact on schooling, and it can be difficult for young carers to speak up and have their needs met.

'It's the same for young carers. Young carers, now, they should be at school. They should be at school full time. But if they care for somebody they – and because, I mean, they have to apply for Centrelink payment. They have to. Being a young carer they actually meet the criteria. However, they're not allowed to attend school full-time.'

'They can't do anything. They can't go up and say, "I'd like to go away for a couple of days", because they definitely don't have anybody there. That's the reason they're being a young carer.'

What things we do outside of our caring roles

As Aboriginal carers we have limited opportunities to do things outside of our caring roles. Some of us have no activities outside of our caring roles., and find it difficult to find time away for ourselves.

'If she wants to go around and see them we can't because I - I have to go with her. If I don't want to go with her, well, she can't go. That's what sort of, you know, ties you down kind of thing'

When we have the chance to do other things we attend 'carer support groups', spend time with our friends and relatives, or engage in other activities. For some of us, attending a 'carer support group' is the only thing we do outside of our caring roles.

'I play bowls. Lawn bowls. Top too. Yeah, almost. That's my Tuesday's and Thursday's; isn't it uncle? Playing a long time.'

'We do the retreats where we take them for a week...You know, they go away and they relax. They do basically what they want to do, but the staff are there to support them. But it still doesn't fit everybody...Some can't go because they just won't leave the caree - because they don't want to be in that situation or, you know, relying on others or they haven't go the assistance there to do it, you know.'





Who helps us in our caring roles

In our role as Aboriginal carers, we get support from our families, friends and neighbours, and the people we are caring for. We rely on our families to assist with household chores or look after the care-receiver which allows us to do other activities such as shopping.

'Sometimes they go with her. Because then once you're up there they've got the family there to help support in that sense. When I go up to Alice Springs I take my sister because we've got sisters who live up there and they'll take us around in a car'

Care is not a one-way street. The people we care for, in our carer roles, also provide support and care for us.

Our families and friends support us emotionally through being available to talk on the phone when we need someone to talk to, or taking over some of the responsibilities of our carer role to give us some personal time.

Our neighbours support us through watching out for us, or checking in with us to make sure that we are okay.

We also get support from government and other service providers, such as carer and disability support organisations, which support us through providing home cleaning services and respite for the people we are caring for.



What's important for us

It is important to us that government recognises the roles that we play in caring for our family members, and cost-savings that this role brings to the government.

Support in our caring roles, and on-going funding to support this

We need support in our caring roles such as assistance with household chores and respite for the people we are caring for. **We need opportunities to engage in activities outside of our caring roles, and support with some of the caring responsibilities to allow this to happen.** This type of assistance provides us, as carers, with opportunities to strengthen our own social and emotional wellbeing.

'Provide services for the carers that can't get out and do any yard work or gardening; for someone to come and clean your house'

'There should be more fun activities for the carers, too, you know. There should be more activities for carers away from town.'

We need access to continued and on-going funding for Aboriginal carers; and support groups which provide us with chances to meet other carers and do things outside of our role as an Aboriginal carer.

Services that are aware of the needs of carers living in regional and remote places

Services need to understand that some of us have to drive long distances to access them, and this takes time and money. **And the criteria for funding to support carers in regional and remote areas needs to take account of the extra costs associated with caring 'out here'.**

'We went to an Aboriginal hostel in Adelaide. The next time we went down that wasn't available and we went to the cancer research place on north Terrace and we got - it cost us \$80 for two. We got back \$60. Then you've got your meals. They don't give you everything everybody else has got, which is understandable. But they don't give you what you lose; you're out of pocket expenses'

'It's, like' \$184 everytime we go to the doctor...So you've got to fork out all this money'

'Yeah, but this is through the hospital now. This is Medicare Local through the hospital, will assist but you have to meet their criteria. And if you don't meet their criteria then you don't get assisted. But then when they do assist you, you only get a certain amount.'

'And they don't care in Adelaide, you know, they don't think you've got to drive three hours to get there so you can go early.'

Advocates - employed on full-time and on-going basis

We need advocates who are employed on a full-time and on-going basis who can either advocate for Aboriginal carers, or can assist us with advocating for our own rights and needs.

Affordable health and dental services

We have our own needs as carers. We need to be able to access affordable health and dental services.

Access to information about changes to policies, services and funding

In order to make informed decisions about the choices before us, we need timely access to information about proposed changes to Aboriginal, carer, and disability policies, services and funding.

Make it easier for Aboriginal people to become volunteers

Making it easier for Aboriginal people to become volunteers would provide support to the carers and the caree.

'Make it easy for volunteers to be brought in. Because as an Aboriginal person it's very daunting to come in and fill all that paperwork in, you know. Then we have to - then they have to have a police check done. The minute you say police check, " No, don't worry about it. Not going any further." But it's having, you know, a volunteer come in whose Aboriginal to be able to help hand your washing our or, know know, do your gardening, you know, mow your lawn for you.'

'And it's the carers who want to be able to become those volunteers because they've been us. Especially the past carers. They've been there, they've done that. They know, you know, they've worked that, well, not worked in it, but they've - the person that they cared for were in that same situation. So bringing them in as a volunteer to support them as a carer would be great.'

What will happen with this research now?

The SPRC will bring together the different parts of the research into a report for policy makers and service providers about how to improve social inclusion for carers. This includes:

- findings from the literature reviews
- data and policy analysis
- findings from focus groups with Aboriginal and non-Aboriginal carers.

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