

Our experiences as Aboriginal carers

Findings from a 'yarning circle'
held in
Adelaide
Friday 1st May 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 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 northern Adelaide, 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 SPRC researchers 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) and Port Augusta (Carers South Australia – Northern Country Carers) 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; Northern Carers Network (NCN), and Aboriginal carers in Adelaide met a number of times to discuss the research, what it might look like, carers' experiences and the findings from the research. Adelaide, the capital city of South Australia, is located on the southern coast of Australia. The next nearest city is Melbourne, Victoria. Adelaide provides most of the major services for South Australia, including major hospitals, which also service parts of the Northern Territory.

To ensure that process suited the Aboriginal carers in the northern suburbs of Adelaide, we met three times including:

1. First visit/chat on the phone and a face-to-face meeting between SPRC and NCN 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. 'Yarning circles' and the face-to-face presentation of findings was mostly made up of younger and middle aged female carers. However, young carers and 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 northern Adelaide. 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. The findings will help form the basis of indicators for social inclusion for Aboriginal carers.

How we became carers

We became carers through a mixture 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 in these circumstances 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 don't call it caring. That's part of our culture'

Caring is not distinct from healing either. Aboriginal carers carry trauma that is the direct result of colonisation. In our roles as Aboriginal carers we are faced with the challenges of supporting people who carry trauma, while also trying to heal our own trauma.

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



'I did it because I wanted to. You know, if you're needed you're needed.'



'Family orientated with our culture it has always been there. It's in our culture.'



'A lot of people that we meet and we say 'oh you're a carer', 'no I'm not', and you go 'you are'



Recognition as a carer

We, as carers, do not always recognise ourselves as 'carers', but consider the role that we play as a carer is just part of our normal role as grandparents, children, spouses or parents.

'Some of them don't even recognise they're carers because of the marriage vows 'till death do us part.'

The term 'carer' is also a term that we do not always identify with. It comes across as a very medical term, and not one that Aboriginal people readily and easily identify with. For instance, Aboriginal people who care for their grandchildren we call 'grannies'.

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

A boriginal carers play a large number of roles from daily up-keep of a house (e.g. cooking meals, washing, mowing lawns, cleaning), to the broader aspects of advocacy, decision-making, monitoring changes, being on-call and protecting the care-receiver. These roles are on-going and do not stop when someone reaches a milestone (i.e. such as turning 18 or reaching retirement age).

Each of these roles requires a certain level and kind of knowledge and skills such as changing dressings, feeding tubes, and monitoring medications. Being a carer also requires the ability to navigate conflict or difficult situations with family members, service providers and those we provide care for.

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
- Watch for changes in the people we care for
- Protect the people we care for from harrasement and abuse
- Be on-call during the night and day
- On-going care throughout the care-receiver's life
- Everything else in-between
- Cooking
- Bathing
- Washing clothes and dishes
- House cleaning
- Transport



'What's happening is a lot of people are thinking about relinquishing their care of their people that they're looking after because they don't have the support structures and they don't have the financial backing.'



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. Some of us had to leave school to care for our relatives, and this has had longer-term impacts on our education. Some of us have had to give up employment in order to care for the people we love. Many of us come from large families and navigating the responsibilities and obligations to care for someone within our family also brings with it conflict and complex challenges. 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. It is difficult when racism is present and means that we cannot have our voices heard and accepted.

Any major changes to disability policy, support, and funding impacts directly on the people we care for, and it directly affects us as carers. For instance, cuts to carer and disability support and funding has meant that we've had fewer support workers to assist us.

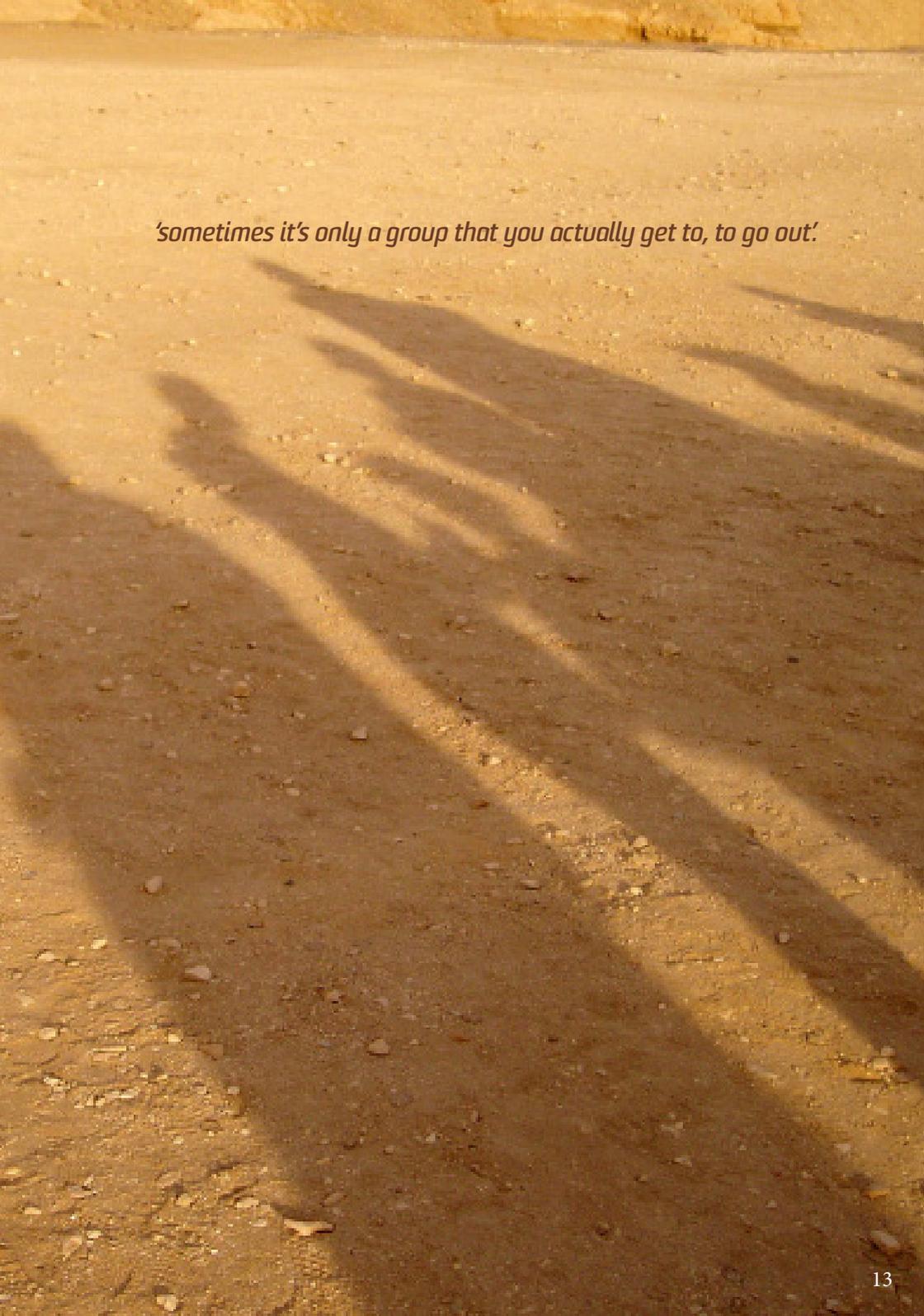
Negotiating with family, service providers and government can be tiresome. Watching some of the changes and how they impact on us is worrisome, and it makes us tired and sick. When funding is cut to carer and disability support, such as to respite care, then we do not get time out to look after ourselves. Without adequate support some of us are choosing to give up our roles as Aboriginal carers.

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

'Carer support groups' are important for us because they give us opportunities to meet with other Aboriginal carers, to hear about changes to carer and disability policy, services and funding (such as the introduction of the National Disability Insurance Scheme, changes to aged care and state funding of carer support services), and to discuss and share some of the challenges we each face as carers. 'Carer support groups' also give us opportunities to meet with like minded people and share some of the great things about being a carer.



A photograph of a sandy beach with long shadows cast across it. The shadows are cast from the left side of the frame, suggesting a low sun position. The sand is light-colored and textured with small pebbles and shells. The background shows a clear horizon line.

'sometimes it's only a group that you actually get to, to go out.'



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 look after the care-receiver which allows us to do other activities such as shopping. We also rely on families to assist with household chores such as washing the dishes, hanging out the clothes and bringing the washing inside.

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

'We help each other. We're there for each other.'

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.

Our human rights to be upheld and respected

As carers we need our human rights to be upheld and respected which includes the right to adequate housing and health care. The government needs to set the relationship right between Indigenous and non-Indigenous peoples in Australia. A treaty, setting out the rights and responsibilities of the State it has for Indigenous Australians, could assist with setting the relationship right.

On-going funding for Aboriginal carers support groups and services

We need access to continued and on-going funding for Aboriginal carers support groups which provide us with the opportunities to meet other Aboriginal carers, how we can care before the people we love, and to learn more about changes to government policies, programs and funding that affect us. This includes the need for appropriate counsellors, respite, appropriate education programs to support carers who are providing full-time care.

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.

Support in our caring roles

We need support in our caring roles such as assistance with household chores and respite for the people we are caring for. This type of assistance provides us, as carers, with opportunities to strengthen our own social and emotional wellbeing. This enables us to continue to provide the much needed care that our family members need. We also need support with how to work through our own trauma, and the trauma of the people we are caring for.

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.

There are a lot of layers to being a carer. The government and service providers need to listen to us when they devise and implement policies and programs that will impact directly upon us, or the people we care for.



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.

To find out more about the research please contact:

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