

Collaboration in achieving recognition of Indigenous family carers

Rosemary Warmington, Carers Association of SA, Janine Haynes, Council of Aboriginal Elders SA, Alwin Chong, Aboriginal Health Council, Dianne Schneider, Carers Association of SA

INTRODUCTION

Indigenous family carers need to be recognised and supported in the significant caring role they undertake in their community. Indigenous carers have identified the need for information and support services that assist them in their caring role. Evidence shows that carers also have their own significant health issues that are largely attributed to their caring roles, and services are also needed to address their own needs as individuals.

The Carers Association, in representing all carers, has identified the need for Indigenous carers to be recognised and provided with culturally appropriate services, often in the midst of complex and challenging social, financial and geographical circumstances.

Since 2002 the Carers Association and the Elders Council in South Australia have worked together to develop programs for carers that are both sustainable and agreed to by the Elders, the local community, carers and the Carers Association.

Those involved have highlighted that there are nine key elements in working together to achieve positive outcomes.

This presentation will use a joint case study approach, to highlight the project and the processes and other key elements in achieving recognition of family carers in the Northern Country Region of SA.

The Carers Association of SA

The Mission of the Carers Association is to promote, assist, empower, and enhance the lives of carers.

The Carers Association of SA to achieve its mission statement, in working with Indigenous carers, seeks to enable and encourage participation and involvement of Aboriginal carers in all levels of the organisation.

The Carers Association is committed to seeking sustainable funding to support Indigenous communities across the state, to support those in the communities who are caring for their people.

The Council of Aboriginal Elders SA

The Council of Aboriginal Elders of SA is a state-wide peak advocacy and information services providing a vital link between aged care service providers and the Aboriginal Community. Its chief role is to monitor the effectiveness of services to frail and older Aboriginal people, ensuring their cultural appropriateness and where necessary to recommend policy changes.

The Council comprises 18 members, who all work in a voluntary capacity, from the 15 regions throughout the state who are nominated by their local regional forum. All members must be over 60 years. The Council secretariat is currently located within the Department for Aboriginal Affairs and Reconciliation.

Partnership between the Carers Association of SA and the Council of Aboriginal Elders SA

The Carers Association of SA and the Council of Aboriginal Elders SA developed a partnership relationship in 2000 to work together in advancing the needs of all Indigenous carers. As part of this relationship, the Carers Association ensures that any activity undertaken with regard to Indigenous carers is respectful of the important role of the Elders in the Indigenous communities. The Carers Association keeps the Council informed of any activities impacting on Indigenous carers and ensures that any new initiatives have the endorsement and support of the Council.

The Carers Association and Council of Aboriginal Elders are supportive of the Iga Warta principles May 1999.

THE PROJECT

A one off one year HACC grant of \$46 000 was provided to develop a model of support for Indigenous carers of children with disabilities in Port Augusta in 2003.

The people and the city

Port Augusta is a city at the northern tip of Spencer Gulf in South Australia. The 1996 Census shows that 14 244 people live in the city; of these 1917 are Indigenous people. The three main local Indigenous communities are the

- Banggarla
- Adynyamathanha
- Nugunu.

Peoples from many other Aboriginal communities also live in Port Augusta.

Historically Aboriginal people were moved to live in Davenport Reserve (now Davenport Community). Children were also placed at Colebrook home in Quorn and Umewarra Mission home in Port Augusta.

As Port Augusta is a major regional centre for health services, many Aboriginal people come to Port Augusta short term for these services.

PROJECT OBJECTIVES

The objectives of the project identified 7 main outcomes to be achieved in a context of working in partnership with Council of Aboriginal Elders of SA and the Port Augusta Aboriginal community, within the city of Port Augusta, in collaboration with the local Elders Group, key services, HACC funded services, local Indigenous services and local Indigenous carers of children with disabilities who are up to the age of 25 years.

A report on this project is available through the Carers Association website.

Project description

The grant employed a part project worker based in the Carers Association – Northern Country Carers office in Port Augusta and funded an independent evaluation.

The Project worker, Lorraine Treloar was employed to identify and connect with Indigenous carers of children with disability in Port Augusta.

The Project had a Project Management Group and Project Reference Group. Forums were organised for carers, Elders and agency workers to meet together, share carer stories and information about services. Forums for agency workers were held and social activities were arranged for carers to meet together. The Project developed information sheets for carers about services. Pathways to connect carers with agencies were developed.

Project participants

At the beginning of this project, Disability Services Office reported that there were 6 children under 25 years of age registered with Options Co-ordination. At the end of the Project seventeen families with 17 children with disabilities under the age of 25 years had registered with the project.

Project completion

This project was completed in November 2003. An application for further funding to extend the project was made. A further one off grant was received in June 2004 for a two year period for \$47 000 in effect half the first grant, with an unchanged project description.

PARTNERSHIP ELEMENTS

In developing the partnership we identified nine elements which underpinned the partnership, are vital to hold the partnership together and ensure that the development of any work is respectful of all parties.

These nine elements are:

- 1 Respect of the Elders' role
- 2 Parties in their collaboration need to take the time and hold steadfast to the agreed approach, even in the face of mounting Government pressure and funding processes and their desire for a quick fix.
- 3 Establishing ethical practices
- 4 Developing, nurturing and sustaining close relationships
- 5 Mutual respect and trust
- 6 Understanding cultural protocols
- 7 Social action and community involvement associated with primary health care

- 8 Establishing agreed to approach and working protocols
- 9 Ensuring simple acts of witnessing along the pathways of partnership.

1. Respect of the Elders' role

In developing a partnership with the Council of Elders, the Carers Association undertook not to proceed with any proposal regarding Indigenous family carers without the endorsement of the Council. At every step of the journey, there was consultation with the Council of Aboriginal Elders over many meetings to arrive at an agreed to approach. This gave plenty of time for reflection, consultation, and then coming together to reach agreement.

Mindful of the importance of having Elders involved with the project, the Carers Association and Council agreed that the Council of Elders elected regional representative Clara Coulthard, who is also a carer, be involved in the project on Project Management group and Reference group. To establish the link further Clara was also invite to become a Carer Ambassador and later became an elected Board member of the Carers Association.

One of the project objectives was to work in collaboration with the local Elders Group. To best facilitate this three local Elders were invited to be part of the Reference Group.

Elders were invited to attend all of the carer forums. Many of the Elders were also carers. Their participation enabled them to know what was happening in the project, and therefore in their community, as well as get information about services to assist them.

2. Taking the time and holding steadfast to the agreed approach

This project came as a result of a long standing but unrealised commitment to develop a strategy for a state-wide network of support for all Indigenous carers dating from June 1999. What was sought was a state-wide network of support programs for Indigenous carers. What was offered was, disappointingly, a one off short term fixed project for a specific group of carers in a specific location.

In February 2000, a funding application was made for the 2000–01 HACC funding round for a state-wide recurrent Aboriginal Carer Support Program. In response HACC proposed that a specific one off project be undertaken in the Port Augusta region with families of children with disabilities.

The Council of Aboriginal Elders and the Carers Association met a number of times at Council meetings and with funding body representatives regarding this proposal.

In July 2002 and September 2002 agreements were reached to proceed with the project as a partnership between the Council and the Carers Association. A Project brief was finalised in October 2002 and funding agreements finalised in December 2002.

There was a great deal of pressure by the funding body on the Association and Council to respond to the offer of this first grant quickly. However the Association's Board and Council of Elders ensured that as much time as needed was taken to reach a mutual agreement which sat comfortably with everyone and was acceptable within the ethical framework of the partnership relationship.

This process of talking and reflecting about the impact of accepting this grant took nearly eighteen months before the Association and Council agreed to go ahead together.

3. Establishing ethical practices

The Council of Aboriginal Elders and the Carers Association met a number of times at Council meetings and with funding body representatives regarding this proposal.

Both organisations were mindful of the Iga Warta principles May 1999 regarding projects being sustainable, having a proactive and preventive approach, addressing environmental determinants, having an Aboriginal community and family approach, being respectful of Aboriginal time and space and addressing the need for co-ordination and continuity between regions and Adelaide.

This funding offer posed many dilemmas for the Association and Council and required many meetings to address the following:

- the grant was one year one off funding with the pressure to achieve outcomes in a short time
- in agreeing to be involved how the Carers Association could continue some support for carers at the end of the project
- the target group was only Indigenous carers of children with disability in Port Augusta, even though there were other families with children with disability of the same communities groups living in nearby locations
- the potential for divisiveness within the communities because there were other family carers who could not be part of the project
- the impact on other areas of the state not receiving any support.

These matters needed to be very carefully talked through to establish practices which were ethically acceptable.

Eventually the resolutions were to:

- accept the grant as a starting point in developing services
- inform communities, Elders, carers and service providers of the dilemmas faced by the Council and Association
- ensure that local Elders were involved in the project at local level
- develop strategies to provide some ongoing support to Aboriginal carers through the Carers Association – Northern Country Carers region
- maintain the Project's community focus and be inclusive of Indigenous carers and Elders from all communities and all carers who wished to be involved
- continue to seek recurrent state-wide funding.

4. Developing, nurturing and sustaining close relationships

At all levels of the project it was important for relationships to be developed and maintained.

The Executive Director and Manager of Carer Support of the Carers Association met regularly with the Council of Elders to develop and maintain relationships.

Lorraine Treloar, a local Aboriginal woman, was employed by the project to develop relationships between communities, workers and carers.

Elders, carers and key workers were part of the Reference Group and membership was open so that Elders and Council of Elders representatives could be part of the group even if that meant a constantly changing membership.

The Nunga Carers Group, based in Adelaide, is an Aboriginal Carers Group many of whom are Elders, have links with communities across South Australia and a number had lived in Port Augusta. The Nunga Carers Group sent representatives to each Forum to strengthen links and supports amongst carers.

5. Mutual respect and trust

Providing an opportunity for people to meet together and to meet service providers in an informal way was one of the most significant strategies of the Project. The reference group meetings, agency worker meetings and the Forums each had a mix of carers, Elders and service providers.

At these sessions Aboriginal and non-Aboriginal people came together, met one another, shared information and got to know one another better. This contributed greatly to breaking down barriers between people and services. It also provided information about services in a more relaxed and informal way.

Meeting service providers at the Forums gave people an opportunity to decide if they thought help might be available. Usually the person approached by the carer for assistance, was not the service provider concerned, but someone connected to the project who could act as a linking person to the appropriate service provider.

Aboriginal people from Adelaide, who knew and were part of the Carers Association and who had connections into the Port Augusta communities, came to the Forums. Their participation in project activities provided encouragement in developing trust in the Carers Association.

Meeting together many times over the twelve months, enabled mutual respect and trust to develop, be tested and to grow.

6. Understanding cultural protocols

Within the Aboriginal population of Port Augusta there is a cultural diversity with people being from many clans and families including those indigenous to the region, from all parts of South Australia and other states and territories.

The three main groups in the area each have their own Elders group, meeting places and kin connections to particular services. For the project to be effective, it was important to maintain connections with all main Elders groups and services and facilitate participation of all groups. Meeting together on neutral ground reduced some of the difficulties faced in coming together.

Family and community belonging is at the heart of Aboriginal culture and vital for the support and emotional well-being of the individual carer. For many people this involved travelling and visiting with other family members returning often to homelands and attending community events, meetings and funerals. People often went away from Port Augusta for significant periods of time.

The Project needed to take into account this important movement of people, community events and the impact on the whole community of a death and funeral. This meant not all people could attend all events on a regular basis, and events had to be changed or cancelled to fit in with other community priorities.

While this movement of people is very important and vital for the support and emotional well-being of the Indigenous carer, it wasn't always recognised and taken into account by service providers. Services to the carer and family were disrupted because services could not follow people to other regional locations. This meant that Aboriginal families were disadvantaged by lack of understanding of cultural factors and their importance to carers.

7. Social action and community involvement associated with primary health care

The project sought to work in ways which would empower carers within their communities, by recognising the contribution and role of family carers and providing: opportunities for carers, Elders and service providers to meet and interact. These meetings helped to break down barriers, gave information about services, developed other more effective pathways into services and brought people together to strengthen relationships.

Four Carer Forums were held in April, July, September and November 2003 at Arid Lands Botanic Gardens Port Augusta. Carers, Elders and service providers were invited to attend. At each Forum one or two carers shared their story and services provided information about their programs.

Project worker Lorraine Treloar and Project management group member Clara Coulthard provided all the leadership at the forums.

Several carers were asked and were willing to share their story in front of other carers, Elders and service providers. This has never been done before. To do so was a big step for some of the carers, but in each case the result was to produce a sense of pride, services offered help for the family and others were encouraged to know that they were not alone. As carers shared their story of caring, others were encouraged to share and did at subsequent forums.

Being able to meet people face to face and hear about services gave people better information about services and the people to approach. It gave an opportunity to clarify areas of confusion about services which had existed for a long time. It also provided opportunities for questions to be asked and for everyone to hear the answers.

As a result of questions being asked or stories being shared, carers were able to get assistance with services. For example, one carer raised her concerns about Centrelink payments in one of the Forums. She was contacted later by Centrelink and was able to have her payments reviewed and she received additional income. Carers were introduced to services providers for the first time and appointments made for future visits.

Another major activity of the project was to link carers into existing services.

Information about services was provided at the Forums. The Project worker followed up and met with agencies to get information about the services offered, to establish a referral process to link carers into those services and capacity to be with the carer during appointments if the carer requested it.

Often these appointments needed to be changed again and again due to the family being overwhelmed with other family and community priorities and commitments. The Project

Worker needed to keep on following up families so that they can meet with the service providers to get some help.

8. Establishing agreed to approach and working protocols

A number of protocols needed to be put in place to enable the partnership to work and some were developed in the life of the project. These included:

- the Board of the Carers Association would not proceed with any programs with Aboriginal carers unless the Council of Aboriginal Elders agreed and fully endorsed the activity
- discussions with the funding body would be held with the Carers Association and Council together
- the Carers Association would provide a written report for the Council of Elders meetings about Association activities with the Aboriginal carers
- the Carers Association would provide a written report about the Project for the elected Council of Elders local representative to present to Council meetings
- the Project would encourage involvement of Elders from each community in the Reference Group and Forums
- the Project staff would seek to work co-operatively with all parties to encourage collaboration and co-operation
- leadership of the Forums would be provided by Aboriginal people
- Project activities would be cancelled if community events, deaths and funerals occurred
- the Project Management Group and Project Reference Group continually reviewed working practices for the project to ensure that they demonstrated respect, trust and cultural appropriateness.

9. Ensuring simple acts of witnessing along the pathways of partnership

Forums provided an opportunity for Elders, Indigenous carers and service providers to come together to introduce themselves, share stories and provide information about services and access to services.

What was shared was for all to hear and see. All those present were witness to what was said and therefore all were informed and empowered both individually and as communities. For services there was an accountability to follow through and ensure that information as presented was enacted and to follow up matters raised by Elders and carers.

This process gave an opportunity to redress the power that shame and lack of clear, consistent information about services had exerted.

The power of providing a public yet simple opportunity to witness all that occurred at the forums, strengthened many participants to take steps to overcome barriers which previously seemed insurmountable.

CONCLUSION

If there are to be advances in developing meaningful services for Aboriginal carers, partnerships such as the one between the Carers Association and Council of Aboriginal Elders are vital.

For the partnership to be strong there needs to be steadfastness to the agreed approach and task, the development of trust and mutual respect and a willingness to work through key elements that have been identified as vital to making the partnership effective.

If governments wish to improve services to Indigenous carers, partnership approaches such as outlined in this paper need to be supported so that mainstream organisations and Indigenous groups can work together to achieve positive outcomes for Indigenous people.

PRESENTERS

Rosemary Warmington is the Executive Director of the Carers Association of SA, which is the peak body representing all family carers in SA. Rosemary was born and raised in rural South Australia and has many years' experience in government and community services working across policy, funding and service delivery and understands the needs of people in rural and remote regions.

Janine Haynes is the Executive Director of the Council of Aboriginal Elders of SA.

Dianne Schneider is the Manager, Carer Support of the Carers Association of SA.