

TERRITORY CARE PROJECT

Final Report

A project funded under

The National Caring Communities Program

by the Australian Government Department of Health & Ageing

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Project Manager:	Uniting Church Frontier Services.
Evaluator:	Centre for Health Service Development - University of Wollongong
Date:	30 April 2005.

Project commencement date:	**May 2003.**
Project completion date:	**May 2005.**
Fund holder (auspice body):	**Uniting Church – Frontier Services.**
Name of service conducting the project:	**Frontier Services – Central Region, Northern Territory.**

EXECUTIVE SUMMARY

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FINAL REPORT

The Background:

Project Title:	Territory Care Project.
Program:	National Caring Communities Program.
Name of service conducting the project:	Frontier Services – Central Region, NT.
Project Manager:	Uniting Church Frontier Services.
Research Officer/Project Officer:	Jay Nelson.
Project commencement date:	May 2003.
Project completion date:	15 May 2005.
Evaluator:	Centre for Health Service Development - University of Wollongong, NSW.
Fund holder (auspice body):	Uniting Church – Frontier Services.
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The Setting:

The project took place in varied settings. Research was facilitated on the field. For example: In a remote Indigenous setting:

- Large scale grass roots consultation with Indigenous men, women, families and carers occurred at the Hermannsburg, Ali Curung and Docker River Communities. Initially some consultation also occurred at the Mutitjulu community. Grass roots consultation with Indigenous men, women, families and carers also occurred at Finke, Imanpa, Ernabella and to a lesser degree Yuendumu.
- Sixteen (16) town camps within the Central Australia and Barkly Region were consulted with.
- Extensive consultation occurred at the Aged Care Facility in Docker River.
- Extensive consultation occurred with community health clinics and community government councils, respite centres and aged care services at Hermannsburg, Ali Curung and Docker River.

In an urban setting:

- A small number of Indigenous patients at the Alice Springs hospital were consulted with.
- Visiting Indigenous families staying at Aboriginal Hostels in Alice Springs were consulted with.
- Directors of Nursing and Managers of the target Aged Care Facilities were consulted with.
- Indigenous health providers were consulted with. (for example, the NPY Women's Council Aboriginal Corporation – Alice Springs, Nganampa Health Service – Alice Springs, Central Australian Aboriginal Congress – Alice Springs, Anyinginyi Congress Aboriginal Medical Service – Tennant Creek and so on).

Research writing, report writing, advisory group meetings:

- Occurred in the project office located at the Old Timers Aged Care Facility – in a stand alone cottage.
- Advisory Group meetings were held in an urban setting – in Alice Springs at the Commonwealth Department of Health and Aged Care offices.
- The level of commitment by the project officer to the project was high but would not have been possible without the assistance of the Directors of Nursing of the Old Timers and Flynn Lodge Aged Care facilities in Alice Springs. In addition the cultural support provided by the Indigenous co-worker was outstanding.

General environment with which the project took place:

The environment encompassing this project was harsh. The project officer worked in a small cottage on her own with no peers around her. This was restrictive in terms of community networking regarding current palliative care issues and trends relative to the wider perspective of National policies and frameworks about palliative care. However, this was somewhat counter-balanced by the project officer's working history on Indigenous communities in Central Australia, particularly at Docker River – Northern Territory. The familiarity of the project officer to many Indigenous communities within the target region allowed the recording and documentation of sensitive culturally material which may not have otherwise been accessed by a less familiar worker.

Consultation with Indigenous men, women, families and carers took place on the ground. We ate a lot while we all talked. Consultation was in language and facilitated with the assistance of an Indigenous co-worker or friend. Generally, the environment was very harsh. It was either very hot or very cold. A lot of camping and stories were facilitated. For this consultation the project methodology used can be summarised as follows:

- The Project Officer/Research Officer working side-by-side with an Indigenous co-worker;
- The two (2) workers travelled around together talking, listening, eating and scribing;
- The two (2) workers requested permission to enter Aboriginal communities by obtaining permits from the respective Community Government Councils;
- The Indigenous co-worker is standing in front talking about palliative care. or *looking after – finishing up*;
- The Project Officer/Research Officer is walking behind, sitting behind. She (the Project Officer/Research Officer) has been given permission, in language, to write down stories, to record information, to observe and respect confidentiality.

- The two (2) workers advised Traditional Land Owners and Community Government Council's about the project and about what it can achieve for Indigenous men, women, families and carers;
- The two (2) workers consulted with major stakeholders like community health clinics;
- Talking to families and to carers – asking them what they understood or knew about the work "palliative care";
- Asking families and health workers how they want palliative care services delivered;
- Asking Aboriginal communities about their cultural considerations, about family obligation and its/or their relationship to palliative care.

The Project Objectives: (What we planned to do)

The Territory Care Project was split into two operational phases. The project officer developed two (2) detailed operational plans relative to each phase. Through an action research model – relative to each distinct phase the project planned to:

1. Identify and consult with key remote communities to link with urban and remote services in the benchmarking, documentation and implementation of culturally sensitive practices in palliative care of the aged in the Central Australia and Barkly regions.

1. Determine the current level of community capacity to provide palliative care in urban and remote services to the aged in the Central Australia and Barkly regions.

2. Build on community capacity by linking to appropriate palliative care training.

4. Work with urban and remote regional focus groups and key stakeholders to sustain palliative care capacity.

5. Plan the trialling of Australian Palliative Aged Care (APRAC) Curriculum for Phase Two (2) of the project to build palliative care capacity in urban services.

Terms of Reference – Phase Two (2): Territory Care Project.

1. Trial the implementation of the APRAC national project curriculum in residential aged care facilities in the Alice Springs ad Barkly regions.

2. Provide feedback to the APRC project on the implementation of the curriculum.

3. Assist services in remote and urban centres in developing local policy and training in providing culturally sensitive palliative care practices.

The Methodology: (what we did)

1. Recruited a Project Officer;

2. Developed two operational plans. Both plans contained clear project objectives – developed to correlate with the objectives for each operational plan were strategies, performance indicators and timelines;
3. Established an Advisory Committee;
4. Developed Terms of Reference under which the Advisory Committee could operated;
5. Scheduled convened and minuted meetings of the Advisory Committee;
6. Identified three (3) remote Indigenous communities in the service – through analysing highest admission rates to the target Residential Aged Care Facilities from Indigenous communities in the project service;
7. Fed results back to the Advisory Committee;
8. Based the selection on the results;
9. Identified and engaged an Indigenous co-worker to work along side the Project/Research Officer;
10. Visited the target remote Indigenous communities to obtain their agreement to participate in the project;
11. Facilitated community advice sessions about the project;
12. Established levels of community participation;
13. Advised the Community Government Councils of the advice session outcomes;
14. Developed and implemented a communication strategy with the DONS of the target Residential Aged Care Facilities in the project service region;
15. Outlined and discussed the project aims, methodology & evaluation process for phase (1) and (2) of the project;
16. Provided regular updates to the Residential Aged Care Facilities on the progress and outcomes of the remote community phase of the project;
17. Developed remote Indigenous community consultation and formed focus groups on each of the three (3) target communities;
18. Identified the key players on each of the three (3) target communities;
19. Established objectives, outcomes and processes for each focus group;;
20. Facilitated engagement through the community focus groups;
21. Through the community focus groups talked about the words palliative care to families;
22. Spread the word about the project through the communities x 3 bush telegraph;
23. Educated community members about palliative care &about how this could help them, their families and their communities;
24. Used the focus groups - in consultation with the Indigenous co-worker – to develop project strategies for Indigenous project sustainability;
25. Used the focus groups to assess the changes in each community with respect to the base line information;
26. Built a relationship wit the APRAC through regular communication strategies such as phone calls, emails and teleconferencing;
27. Identified appropriate areas of the APRAC curricula to be trialled and identified potential outcomes for best practice;
28. In consultation with the APRAC and the Territory Care Advisory Committee identified a broad methodology and finalised an operational plan for Phase 2 of the Territory Care Project;
29. In consultation with the APRAC and the Territory Care Advisory Committee determine and assess base-line data for the evaluation of Phase two (2) of the project;
30. Developed a communication strategy to engage, inform & update target Residential Aged Care Facilities about Phase of the project;

31. Outlined & discuss the APRAC curricula;
32. Outlined and discussed the rollout of the modules for each Residential Aged Care Facility;
33. Provided regular updates to the Residential Aged Care Facilities on the progress of the trial;
34. Fed back the training outcomes to the ARAC as the trial progressed in the two (2) selected Residential Aged Care Facilities;
35. In consultation with the APRAC, the Territory Care Advisory Group and the target facilities in the project service area identify the appropriate areas of the APRAC curricula to be trialled in each target facility;
36. Identified key strategies to rollout the APRAC curricula in both an urban and community based Residential Aged Care Facility;
37. Looked at strategies to develop an appropriate training style o the APRAC;
38. Selected a trainer;
39. Rolled out the Module to meet the skill level of the individual participants in the two (2) selected Residential Aged Care Facilities;
40. Bench marked the training engagement rates;
41. Benchmarked the risk assessment to participating Residential Aged Care Facilities involved;
42. Benchmarked methods of best practice for palliative care training delivery in both the target facilities;
43. Attempted to develop culturally sensitive palliative care workplace policy and practice through consultation and the development of culturally appropriate palliative care policy and guidelines for urban and remote Residential Aged Care facilities that demonstrate best practice.
44. Based on the above outcomes feedback project outcomes which can substantiate project recommendations to the funding body.

The Results:

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1. There is currently little – if any – scope in the three (3) target Indigenous communities to sustain community based palliative care. This result is based on the outcomes of consultation with the focus groups and senior men, women, community members and family of the research communities. (Refer story – pages 11 and 12 of the final report).
2. Indigenous community members currently have little – if any – concept of the term palliative care.
3. There is a very strong consensus that the western medical system in Central Australia and the Barkley Region(s) does not recognise the importance – both culturally and spiritually – of the Ngangkari (traditional healer).
4. There are few – if any – appropriate resources on the three (3) Indigenous research communities to engage in the caring process of a family member who is dying. This result is relative to lack of appropriate housing which would include outdoor fires and showering facilities, appropriate ramps for beds and wheelchair access, money for medicine, transportation to go for bush tucker and bush medicine, facilities to regularly wash linen and blankets.
5. Currently carers and some Aboriginal Health Workers do not feel comfortable looking after due to inadequate palliative care training. This situation is compounded by the

mitigating factor that services such as the palliative care service – Central Australia – do not even have one Aboriginal Health Worker to visit communities and provide appropriate cultural support.

6. Outcomes from the grass roots research undertaken for this project differ greatly from the key result areas included in the draft NT Palliative Care Strategy 2005 – 2009.
7. Training – or the lack of appropriate training for palliative care Aboriginal Health Workers, Personal Carers, Enrolled Nurses and Registered Nurses – is in absolute crisis in both Residential Aged Care Facilities and hospitals in the Central Australian and Barkley Regions. Research facilitated by this project clearly indicates that health staff has little – if any – idea or skills relative to cultural awareness, spirituality, cultural safety, etc. If proper services are to be provided and staff retention within facilities is to improve over the next five (5) years then this factor along must be look at urgently and funding provided to facilities and hospitals to educate, train and up-skill their workers in these areas.

Finally some objectives of this project unfortunately could not be met. These objectives included the following:

1. Development of a 24 hour phone line in the target Indigenous communities – this could not happen due to non-recurrent funding and the resources to implement this initiative;
2. Internal policy for the two (2) Residential Aged Care Facilities did not occur – i.e. the Old Timers Aged Care Facility at Alice Springs and the Docker River Aged Care Facility at Docker River. For the Old Timers Aged Care Facility this occurred due to limited time constraints and lack of resources to finish this project effectively. For the Docker River Aged Care Facility it was a different story – towards the final stages of the Territory Care Project there were complex internal politics occurring on this community in which the Docker River Aged Care Facility was involved. Unfortunately this suspended the final visit to this community to paint a mural on the outside walls of the Docker River Aged Care Facility and develop the word matching for palliative care on to laminated posters to be hung in the staff room.

The Discussion – In Summary:

Positive:

- Community engagement for this project was excellent. Considering the geographical area that had to be covered, the hours spent driving and camping, the language and cultural barriers – excellent engagement rates occurred for the focus groups, and the training take-up rate for the APRAC roll-out at the Docker River Aged Care Facility was encouraging and pleasing.
- Grassroots field work including consultation and data collection have enabled important recommendations - that can be supported and validated by focus group data collection, training group data collection - to be provided to the funding body. The Territory Care Project has highlighted the fact that currently – in Central Australia and the Barley Regions – there is a severe shortage of resources, training and education to support Indigenous palliative care patients, their families and community members

– this in turn effects community capacity to develop sustainable palliative caring options. **Most importantly patient choice relative to decisions that everyone has the right to make about where they would like to die and be buried**.

Negative:

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- Finishing this project was a major achievement: The project was insufficiently funded to incorporate the value of an Indigenous co-worker to work alongside the non-Indigenous project/research officer. Taking into consideration the high degree of Indigenous consultation required for the objectives in Phase 1 it is a recommendation of this project (refer Recommendation 12 – Final Recommendations) that this situation be reviewed within a funding context for future projects of this nature.
- Geographically the area was large and the degree of work associated with the implementation of the Operational Plans for Phases 1 and 2 – complex time consuming and exhausting. This has – in some areas – impeded on the outcomes of the project. (Refer point 2 – the Results).

Ancillary Comments regarding the Territory Care Project:

- All of the objectives within the operational reports for phase 1 and 2 were important. At the time of developing the plans I felt they were far to complex and cumbersome. I realise now that they provided me with an excellent framework on which to build and conduct this project. Perhaps – in future – if operational plans of this nature are required – then the time provided by the funding body in which to conduct the project be married more appropriately to the time and resources taken to develop operational plans and reports of this complexity and depth. (Refer Appendices 3 – Operational Plan, Phases 1 and 2).
- There is strong evidence to indicate that this project could be duplicated at Ali Curung. The research facilitated by this project on this community indicates that there is a strong willingness by community members to engage in and develop sustainable options for palliative care at Ali Curung. Taking into consideration this community's close proximity to the urban centre of Tennant Creek, the current strength of the community's infrastructure including the Homemakers Centre, the Respite House and the Aged Care Team there are strong indicators that could support the application – or generalisability – of this project in the Ali Curung Community.
- If any lessons are to be gleaned from the operational setting of this project they would include:

(a) That these types of projects best sit with organisations – for example the Menzies School of Health – who have a commitment to research and the professional expertise to support the processes involved in such a complex and important project.

(b) That a lack of peer involvement in a project of this capacity can affect the processes attached with actually facilitating a project of this magnitude. For example: the project/research officer for the Territory Care Project worked alone – in an isolated setting – separate from other organisation peers. This greatly affected the capacity to build relationships and received appropriate project support when required.

(c) As outlined in Recommendation 12 (Ref Final Recommendations – 12) projects of this complexity and depth with a strong Indigenous focus should not be funded without the inclusion of an Indigenous co-worker who can lead the way with language, culture, etiquette and country.

The Conclusion:

That there is a co-ordinated approach amongst all agencies involved in the planning, development and delivery of palliative is services in the Central Australia and Barkley Region(s). A meeting should be convened to discuss future palliative care plans – relevant to any available funding in the 2005 Federal budget – the meeting should be open, holistic and appropriate convened - **it should be representative of appropriate grass roots workers and policy markers who have experience in not only palliative care but culture and spirituality and who can formulate appropriate ideas and solutions.**

That an injection of funding be urgently made available to Residential Aged Care Facilities in the Central Australia and Barkley Region(s) to address current inadequacies in training levels relevant to Indigenous men, women and families and community members exposed to the receipt of palliative care services in a Residential Aged Care Facilities and or Hospitals. This training should include but would not be inclusive too:

- Cultural requirements of Indigenous patients/residents;
- Spiritual requirements of Indigenous patient/residents;
- The importance of the Ngangkari;
- About dying, death and burial – the Indigenous way;
- Importance of where you die and where you are buried;
- Language;
- Family beliefs;
- Family blame and payback;
- The importance of traditional ceremony including singing, dancing (Inma) wailing, and smoking;
- About sorry camp.
- Who can look after whom? – Who cannot look after who?
- Can you say that dead persons name? If not, why not? What name do we give them? What if another family member has that same name as that dead person – what should we call them?

That a review of brokerage pools be undertaken by the Commonwealth and State/Territory governments to increase access to available resources for palliative care, carers and service providers and that the associated Terms of Reference relevant to their use be updated to initiate a more cohesive, cost affective, culturally appropriate, holistic and valuable result.

That the Central Australian Palliative Care Service urgently be provided with at least two (2) Aboriginal Health Workers to work along side non-Indigenous Palliative Care Health Professionals.

That the Australian and State Governments urgently move towards the incorporation of the Ngangkari into the Western Palliative Care Health System and that this incorporation – and its benefits – be urgently recognised and valued by the Alice Springs Hospital and Residential Aged Care Facilities in the Central Australian and Barkley Region(s).

That the Ngangkari be appropriately renumerated for his or her work with palliative care patients and family.

That resources be increased and/or more appropriately managed and directed to better service the needs of Indigenous palliative care clients on remote Indigenous communities of the Central Australian and Barkley Region(s) so as to at least provide a choice for people wanting to stay on their community. **Without this resourcing community capacity to effect palliative care on remote Indigenous communities of the Central Australiana and Barkley Region(s) will never occur**. Funding needs to be more appropriately for training, health professionals, travel, accommodation, transportation, caring aides, every-day living aides, carer's payment, medicine and so on.

That resources be increased for staffing levels in Residential Aged Care Facilities in the Central Australia and Barkley Region(s) which make it possible and culturally appropriate for male health professionals (including personal carers and Aboriginal Health Workers – taking into consideration cultural boundaries such as initiation and family hierarchy) to care for men and women to care for women (including personal carers and Aboriginal Health Workers – taking into consideration the appropriate cultural hierarchy of grandmothers, mothers, grandchildren and others).

That an organisation be urgently funded to provide appropriate transport requirements – one in the Central Australia Region and one in the Barkley Region for the transportation and support from remote Indigenous communities to urban based services – and between services in Alice Springs and/or Tennant Creek to properly and adequately support Indigenous medical and family palliative care requirements. That perhaps this service forms part of already existing service such as a Carer Respite Centre or a Palliative Care Service.

That appropriate and affordable access to accommodation is urgently addressed by both the Australian and State Government to allow Indigenous family members and Aboriginal Health Workers to support a friend and/or family who are finishing up – either in community or in an urban based facility.

That the draft APRAC Guidelines and Curriculum be redrafted – in the areas identified within this final report of the Territory Care Project – to more adequately and appropriately address culture, cultural safety and spirituality relevant to the high Indigenous population of the Central Australia and Barkley Region(s). Specifically – the review of Chapter 9 of the APRAC Guidelines and Curriculum and the insertion of a chapter on Cultural Safety.

That State and Commonwealth funded projects which specifically require a large proportion of Indigenous research be funded to incorporate the use of an Indigenous co-worker to work alongside the non-Indigenous project officer/research worker. Without this resource projects like the Territory Care Project and other projects that will follow after it – not only because the research would hold little – if any cultural appropriateness or credence in an Indigenous environment – but because cultural and language barriers greatly impede the ability to effectively and competently research the subject topic.
