

Newsletter

SECOND ISSUE



APRIL 2008

Second Steering Committee Meeting

The second face to face meeting of the Indigenous Dementia Services Study Steering Committee was held in Broome on the 12th March 2008.

Pictured are all of those who attended. Apologies were received from Michelle Skinner, Maxine Nixon, Ivy Till, Jan Lewis, Heather Umbagai, Janet Oobagooma and Dr Nicolette DeZoete.

During the meeting there was a lot of discussion about dementia / memory problems and peoples experiences of this illness with family in the Kimberley. The findings from the scoping study interviews with service providers were also considered (see page two).

The steering committee were joined for morning tea by Nicola Lautenschlager, Leon



Steering Committee Members from left to right: Mena Lewis, Pauline Manning, Ruth Umbagai, Ronald Mosquito, Andrew Cox and Lincoln Mosquito

Flicker and David Atkinson. Nicola and Leon spoke about the WA Centre for Health and Ageing.

After morning tea the Steering committee broke into women's and men's groups to refine the in-depth interview questions for carers and workers (see page five).

Steering committee members spoke strongly about the need to improve awareness and support for people with dementia and their family carers (see page five).

It was a great meeting and our thanks to everyone who traveled to attend.



From left to right:
Lincoln Mosquito, Andrew Cox, Nicola Lautenschlager, David Atkinson, Ronald Mosquito, Leon Flicker, Ruth Umbagai, Mena Lewis, Geraldine Shadforth, Kate Smith and Pauline Manning

Older Indigenous People

The stories of older Indigenous Australians speak of survivorship and of statesmanship. This was obvious to Warburton and Chambers (2007) when they looked at all available books, reports and DVD's or interviews describing the modern day roles of older Indigenous Australians. They found that older peoples make important contributions to their community through sitting on boards or committees to speak up for fair access to health, housing, employment and education as well as political and cultural rights; to their families by caring for children and young people as well as other family members in difficulty; and in promoting education by the passing on of language and culture knowledge. To be able to age successfully is the desire of Indigenous peoples (Arabena, 2007). The main concerns for successful ageing voiced by senior Aboriginal people in central Australia on Ngaanyatjarra Pitjantjatjara Yankunytjatjara lands included; living circumstances which maintain dignity and enhance self-esteem; being able to participate in traditional and community activities; being able to visit traditional country; being with one's family; not having to send one's spouse or other family member elsewhere to be cared for; having a say in how you get help; getting help when you need it; growing old and finally dying in one's country; being buried on one's country; and having the acknowledged rights to all of the above (p. 84, NPY Women's Council Aboriginal Corporation, 1995). More recently, at the National Indigenous Dementia Workshop it was decided that successful ageing required reducing chronic disease and the effects of disease; encouraging mental and physical functioning in respect of lifetime learning; and supporting an active engagement with life as grounded in key social relationships and living in safe cultural contexts (Alzheimer's Australia, 2006).



Michelle Skinner with her sister
in Looma

Dementia / Memory Problems

The KICA

(Kimberley Indigenous Cognitive Assessment)

In 2003 to 2004 the KICA was developed and validated. Before the KICA there were no appropriate tests to assess dementia with Aboriginal people. Because of this, the number of Aboriginal people with dementia was largely unknown, and many people missed out on treatments. The KICA is now widely used by clinicians in the Kimberley and has also been validated in the Northern Territory, with a trial currently underway in Queensland.



Laurie Churnside
taking blood pressure

Indigenous Dementia

Services Study

The current study aims to address the unmet needs of Aboriginal people living with dementia and their family carers in remote communities.

This will first involve interviewing by phone service providers and then speaking face to face with community based workers and family carers. This information will then go to focus groups in community, so communities can determine the best ways to care for older people with dementia. The study team will then work with services and communities to try out these new approaches and to evaluate if they work.

It is acknowledged that *'one size won't fit all'*, and that several different models of care will need to be developed and trialed as decided by each community. This third stage is funded by a NH&NMRC grant to run in the Kimberley over 2007 to 2008, and in the Pilbara over 2008 to 2009.

The Prevalence of Dementia

Using the KICA, a second study was conducted over 2005 to 2006 to find out how common dementia is amongst Aboriginal people in the Kimberley. Dementia was found to be very common, with 12.5% of people over the age of 45 years having the condition. This rate is substantially higher than the prevalence of dementia in non Indigenous Australians, particularly in the 45-59 year age group. The risk factors for dementia were found to include; being male, older or a current smoker, as well as having a history of a stroke, head injury or epilepsy.



Ronald Mosquito doing a KICA
assessment in Balgo

New Dementia Poster..



A new poster on the signs, causes and risk factors for dementia amongst Indigenous people has been released.

The artwork was developed by Anna Dwyer, project officer with the study until end of 2007. Michael Torres with the KAMSC Health Promotion Unit then developed the artwork into the final poster.

If you would like copies please contact the IDSS Team

Scoping Study Findings...

The purpose of the scoping study was to find out what services are currently available for older people with dementia and their carers in community. Also, to find out the strengths or difficulties experienced by service providers and any suggestions of how to improve dementia care.

42 people were interviewed (mostly by phone) from services across the Kimberly. All of the interviews were confidential. The information from the interviews was then analysed, with interesting comments and common threads in what people were saying becoming the main themes found to effect services to Aboriginal people with dementia in remote communities.

These included;

- * **issues effecting remote communities** (distance, competing priorities of need where everything is needed, acceptance of changes in older person, need for practical support for carers, elder abuse, strengths of art and of country)
- * **issues effecting service providers** (relationships and communication between service providers and with families, the strength of flexible service provision, use of interpreters, assessments, referrals and the need for clinical pathways, protocols and guidelines, and gaps in services)
- * **issues with workforce** (increasing the Indigenous workforce, valuing aged care workers, cultural safety in the workplace and barriers to Indigenous people

ple entering the workforce)

- * **the need for training** was mentioned (including training for managers, clinicians, aged care workers and community members and carers on topics such as cultural awareness, using the KICA and more generally what is dementia and how to care for someone with dementia)
- * **the need for projects** to help people with dementia and their carers that are **based in the community** (so people can stay on country), are community driven and self determined, and the importance of shared cultural understanding to shape projects
- * other topics came up about the importance and **strength of cultural knowledge, spirituality, family and kinship roles.**

Mowanjum Pensioner Units

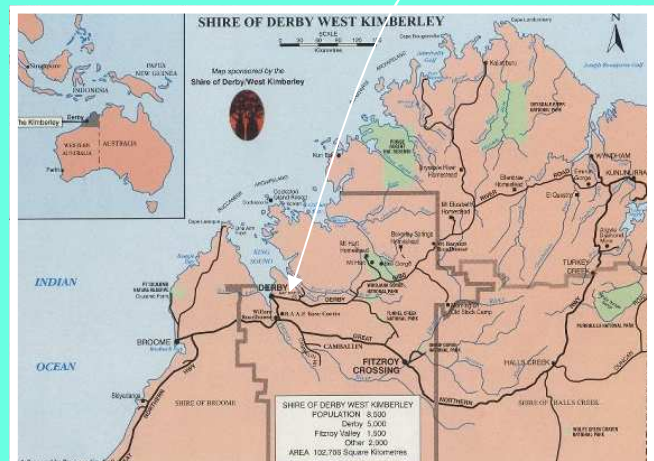


Hello my name is Andrew Cox I am the HACC manager here at Mowanjum community which is 6 kms out of Derby WA. My partner Yvonne is the assistant manager. We have six workers, and the things we do is cooking, cleaning, gardening we also get HACC support from town to do meals around the community.

There are six clients in the community and six clients in the pensioner units. We also take clients to town to do banking, shopping and what ever their needs are; we also work with the remote area coordinator to ensure all elderly "at risk" are known and to develop a care plan for each person with the Remote Area Coordinator. I also explain to the people who are receiving meals about chuck-in and get their permission to have money taken from their pension.

I represent HACC at Council meetings and raise issues on behalf of HACC and also contact the Remote Area Coordinator with any issues surrounding HACC projects. We also do tick sheets (check lists) that we send to Broome every week.

We make sure HACC clients will be OK over the holiday period and encourage family members to visit clients.



Mowanjum Pensioner Units



Residents relaxing at the Pensioner Units

Alphonse Buck cooking kangaroo



Andrew Cox (HACC Manager,) Alphonse Buck (worker), Henry Duckhole, Jimmy Malani and Michael Bear outside the Pensioner Units

Suggestions From The Steering Committee

The Steering Committee suggested the following ways to improve support for people living with dementia;

- * Information on power of attorney and the legal right for family carers to speak for the person with dementia
- * Education about Dementia to begin at schools
- * More Aboriginal Health Workers trained in dementia / aged care
- * If the older person is staying in town or city, have photo's of their country and family on display so they feel safer, reassured. The issue of people having passed away and photos was discussed
- * Formal carers (eg. hostel staff, HACC) can ask family members what the person with dementia likes to do and for other suggestions on keeping the older person happy. For example music, dancing, raking the garden
- * Using traditional healers first when the changes in the older person are thought to be because of cultural reasons,
- * Need for more financial support for carers
- * Finding ways to help carers to cope better
- * More posters and pamphlets on what dementia is
- * Holding family days bringing together older and young people
- * An orientation package for non-Indigenous staff that is specific to the community they are working in. It was acknowledged that there are already general 'Ways of Working' packages that most staff are given during orientation, but for the person to be able to work well in that community, they need to have more information on that specific community and region
- * To have an article in this newsletter on the Mowanjum pensioner units (see page 4 and 5)

Suggestions From The

Chief Investigators...

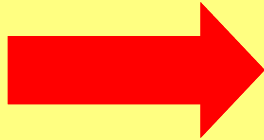
The Chief Investigators for the IDSS study met in Broome on the 10th and 11th March, 2008. Findings from the literature review and scoping study were considered as well as the anticipated future direction of the study.

To set the Kimberley scene, David Atkinson spoke about primary health care in the region, Jenny Poelina spoke about Aboriginal Health Worker training (both with the Kimberley Aboriginal Medical Services Council), Monica Frain with the Kimberley Population Health Unit spoke in relation to the remote area nurses and Jan Lewis with Department of Health and Ageing spoke informally about funding in the region.

From discussing the Scoping Study findings, the Chief Investigators suggested the following;

- * Need for a clearer understanding of elder abuse, what is the right term, how is it locally defined
- * Promotion of positive care
- * Does increasing awareness of dementia as a disease improve care, alternately does a lack of this kind of knowledge result in harm
- * Best practice guidelines for rural and remote Indigenous dementia
- * Practical information for carers in pamphlet on dementia management
- * Executive summary of Scoping Study findings and full report to be written and widely distributed through networks

What We Are Doing Now...



1 Form Steering Committee to guide project

2 Scoping Survey interviews with service providers to have a clear picture of current dementia services in the Kimberley

3 In depth interviews with up to 20 family carers and workers that look after people dementia in remote community.

4 Analysis of in-depth interviews

5 Develop emerging themes into a dementia specific model of care

6 Community based focus groups to discuss and determine final models

7 Pilot and evaluate care models in community

The steering committee were instrumental in developing the interview questions for carers and workers. For example...

Question...

You got some other mob helping you?

Prompts...

1. *Countryman?*
2. *You got anyone else coming in from outside the community?*
3. *Anyone else in the community helping you?*

For the in depth interviews with carers and workers Geraldine and Naomi will be visiting Mowanjum, Derby, Looma, Warmun and Balgo over April and May

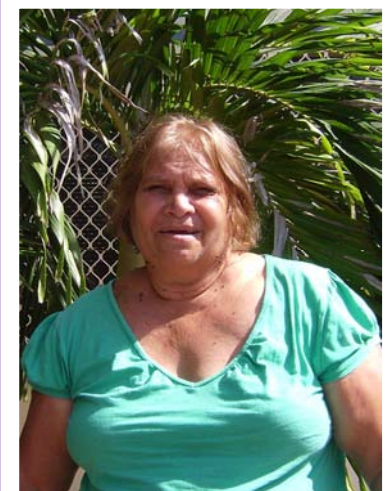


New Staff Member...

My name is Geraldine Shadforth. I was born in Broome, WA. My Mother was a Bardi woman but my father came from QLD. When I am asked where I come from I say my father comes from the rising sun and my mother from the setting sun. I have been working in the health area since the late seventies early eighties, we were known as Camp Nurses.

I have watched the changes regarding Aboriginal Health Workers and I am pleased to see great things happening.

I am now employed as a project officer and my role is to assist in the conduct of the Indigenous Dementia Services Study and I find this very interesting. I have always wanted to help old people.



Anyone interested in dementia can specialize in this area after their health worker training.

Who's working on this project?



Dr. Dina loGiudice²
Chief Investigator
& Principal supervisor



Dr David Atkinson^{3,4}
Chief Investigator



Prof. Orvaldo Almeida¹
Chief Investigator



Prof. Leon Flicker¹
Chief Investigator



Jocelyn Jones¹
Associate Investigator &
Indigenous policy consultant



Prof. Nicola Lautenschlager¹
Chief Investigator



Kate Smith¹
Chief Investigator &
Project Manager



Frank Schaper¹
Associate Investigator



Melissa Lindeman⁵
Associate Investigator &
Qualitative researcher



Geraldine Shadforth¹
Project Officer



Naomi Ralph¹
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Indigenous Dementia Services Study Team

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