Indigenous Services Study:
Lungurra Ngoora Community Care Final Report

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Acknowledgements

Cover photo: Visiting country. Photo:McGaffin

Executive summary

Background

Despite many efforts, the gaps in services for Indigenous Australians living in remote communities continue. A recent study conducted in the Kimberley region of Western Australia by The University of Western Australia demonstrated a high prevalence of dementia in Aboriginal communities. This finding led to the development of this research project which was conducted in three stages. The first stage involved a literature review of service gaps and current care initiatives for remote Aboriginal community care for the frail aged and people with disabilities. The second stage involved a qualitative study to determine the unmet needs of Aboriginal people with dementia and their caregivers living in the Kimberley region. The results of this unmet needs study are presented in section II of this report. The third stage involved utilising the results from this study to develop and trial a community care model to meet the needs of the frail aged, and people of all ages with disabilities and mental illness living in remote Aboriginal communities. Section three will outline the development and the final evaluation of this model of care. These results will be supplemented by an independent qualitative evaluation completed by Rhonda Murphy of Yarmintali Consultancy, which is available separately on www.wacha.org.au. The 12 month financial report was not available from Kimberley Aged and Community Services (the project fund holder) at the time of writing and is to be lodged by KACS on 30th September 2010.

Methods

The Unmet needs Study (Section II): A steering committee comprising past and present Aboriginal caregivers, remote community representatives, and service providers was formed to advise and guide the research project. Kimberley service providers (n=42), caregivers of Aboriginal people with dementia (n=16) and remote community-based HACC workers (n=15) were interviewed by Kimberley-based research staff to determine the scope of the services in the region and the unmet needs of people with dementia and their caregivers.

The Lungurra Ngoora Pilot Project (Section III): The model was developed based on the outcomes of the unmet need study. Focus groups were formed to maximise consultation, represent the needs of the community and to develop and endorse the project. The pilot involved

provision of care to those who were traditionally in receipt of services by aged care, mental health and disability services. The pilot was funded by Home and Community Care (Department of Health WA), Western Australian Country Health-Mental Health Service and the Disability Services Commission. Utilising a mixed method approach of both quantitative and qualitative data, an evaluation of services was made at baseline, six months and twelve months in several key areas. Data were acquired based on tick sheet reports (weekly summaries of services provided in the community), from feedback forms from clients and carers, and testimonials from service providers and the community. These outcomes are supplemented by an independent evaluation report that is available on the website (www.wacha.org.au).

The study protocol was approved by Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC) and the University of Western Australia Ethics Committee for Human Research. Community council and individual approval was sought and gained.

Results

The Unmet needs Study (Section II): The results from the interviews strongly indicated many areas of unmet needs in the Kimberley. The key unmet needs identified were genuine community consultation, service coordination and communication, community based services, culturally secure services, Aboriginal workforce with local guidance and support, and education and training.

Lungurra Ngoora Pilot Project (Section III): In the twelve month period the client base grew from 8 clients to 22 clients utilizing services. The number of services provided grew from 140 services at baseline to 2395 services at twelve months. A total of 18,541 services were received by clients from 13.7.09-11.6.10. Greater collaboration and coordination of services occurred as well as high client and community satisfaction with the range of services (measured through feedback forms). Strong support was gained from local businesses who donated goods throughout the project. Looma Council reported strong approval for the consultative and on the ground nature of the service, and for the employment and ongoing training of community members. External service providers have reported increases in efficiency through co-owning a community-based service and marked improvements in the health and well-being of their clients.

Conclusion

There have been dramatic improvements in service delivery in Looma community over the trial period. The model of care, based on extensive research of community needs, can provide more effective and equitable remote service delivery to the frail aged, people of all aged with disabilities and mental illness, and their caregivers living in remote Aboriginal communities. The Lungurra Ngoora Community Care Service has been embraced by the Looma Community. Due to the nature of the model the project was flexible enough to withstand the challenges often faced in remote communities. There is potential for expansion of the key components of this model to other areas given genuine collaboration and consultation with interested communities.

Key Recommendations

The following recommendations were developed through extensive consultation with stakeholders both prior to and during the trial, and are crucial to the future success and sustainability of the model. These recommendations address the unmet needs identified in section two, namely genuine community consultation, service coordination and communication, community based services, culturally secure services, Aboriginal workforce with local guidance and support, and education and training.

> ➢ **Formal partnerships, cooperation and collaboration** between service providers and community. The model ensures the formal collaboration of service providers with each other and the Aboriginal community at all levels. The steering committee co-funds and co-directs the project, assisted in the collaboration process by the independent facilitator. Organisations commit to and sign a service agreement which identifies the shared objectives that they co-developed and outlines their role. The values of mutual respect, ability to be flexible and innovative, and to work within a team are key attributes for the steering committee. The guidance of the steering committee and the local action group is invaluable for the success of the project.
>
> ➢ **Genuine community consultation, guidance and decision making**. The community must be involved in all aspects of decision making including project design, consultation, management and feedback. Decreasing reliance on transient positions (such as the community CEO) through formal community council engagement at the strategic management level prevents regular changes in the administration staff from halting the delivery of services. The regular survey of community clients and caregivers on ways to improve the service is recommended.

- An **independent facilitator** to ensure collaboration and assist with direction of common goals. If possible the role should be filled by a non-government organisation to assist in facilitating the variety of specialised service providers and industry to work together with the community and pool resources to provide one on-the-ground service, to mediate interests, to ensure a focus on community development and to engage local businesses. It is recommended that the facilitator holds the project funds and employs staff members to simplify administrative procedures.
- **Flexibility** of service providers, staff and the service. The service needs to be flexible and responsive to the needs of clients, caregivers, the community and the staff. It is recommended that a pool of community-based workers are employed and trained to provide a range of services (see recommended model of care, figure 13, p.58).
- **Culturally secure and community-based service.** Employment of preferably Aboriginal staff members who are supported in the community and guidance from the community council capitalises on local knowledge and builds community capacity. It also enables the service to meet the specific needs of each community. It is recommended that the project coordinator works with the community council to identify and recommend potential workers from the community. This also enables positions to be filled quickly.
- **Community based support, mentorship, training and development of staff.** It is recommended that steering committee and local action group members are actively encouraged at each meeting to identify new training opportunities and resources available to the community members and project staff and assist in accessing these. The community-based project coordinator provides day to day mentorship and support to the staff. The independent facilitator manages and supports the project coordinator with support from the community council. As transport is a key issue for clients and caregivers, all project staff should be supported to gain their driver's licence where possible.
- Ongoing **advocacy** for clients and families. The project coordinator provides one access point in the community for clients, caregivers, the council and service providers. This has assisted in the smooth delivery of services. Outstanding service delivery issues for clients and caregivers (such as installation of equipment, need for an interpreter or health care issues) can be efficiently followed-up by the project coordinator, or jointly coordinated at local action group meetings.

Section One: A Literature Review

Introduction

Indigenous Australians have the worst health status of any population in Australia, with high levels of chronic disease and injury contributing to the development of functional disability at a younger age[1]. This is also reflected in the results of a Northern Territory study[2] in which the disease and injury burden of Indigenous Australians of the region exceeded that of the non-Indigenous sample who were approximately 20 years older. A higher proportion of Indigenous Australians are living in rural and remote areas than the wider Australian population[3]. The importance of improving service delivery for Indigenous Australians living in remote communities is highlighted in key strategic directions set by the Australian Government. These include the Council of Australian Governments (COAG) priority of improving remote service delivery to Aboriginal communities to close the gap on Indigenous disadvantage[4], and the strategic directions of the Australian Department of Health and Ageing which include to improve access to, and responsiveness of, the mainstream health system for Indigenous Australians, and to collaborate across governments and the health sector to improve service delivery and outcomes for Indigenous Australians[5]. This section reviews the available literature regarding the service gaps and current initiatives related to community care for Aboriginal people living in remote communities.

Methodology

Literature searches revealed a paucity of information specifically related to the topic of Indigenous or Aboriginal aged and disability care in remote communities in Australia. Relevant databases, government and non government publications and health websites were searched. These include, but are not limited to: The World Health Organisation, Alzheimer's Australia, Carers Australia, Australian Department of Health, Western Australian Department of Health. As well as this, search engines such as PubMed, ProQuest and Google Scholar were utilized to access peer reviewed journals and case studies. The key words in the searches included (but were not limited to): Aboriginal aged/disability care, rural/remote Aboriginal health, rural/remote aged/disability care, Aboriginal health, Aboriginal health/disability policy/services/initiatives, cultural security, service gaps in rural/remote health/Aboriginal health and related search words.

Results

Indigenous health and disability

Indigenous people are heterogeneous, possessing diverse language and skin groups[6].The total population of Indigenous Australians is 517,200, 2.5% of the Australian population[3]. In 2008, the average life expectancy for Indigenous men and women was 59 years and 65 years compared to 77 years and 82 years in the non-Indigenous population[7]. There are also high rates of chronic disease, suicide and disability in the Indigenous population[8].

It is well known that a diverse range of factors impact upon health of Indigenous Australians, including vulnerability to disease, colonization, lifestyle factors, socio-economic factors and education[9]. In addition those from a lower socio economic background are more likely to participate in risky behaviours and are less likely to use preventative health services[10].

Recent reports suggest that the Aboriginal population experience rates of severe or profound core activity limitation or disability that are 1.3-1.5 greater than the non-Indigenous population[11,12]. This is remarkable as the Indigenous population has a much younger age structure, and rates of disability rise dramatically in the non-Indigenous population after the age of 65 years. The AIHW[7] indicate that the most commonly reported disabilities of Indigenous service users are intellectual (39%), physical disabilities (14%) and psychiatric (12%). This is similar to non-Indigenous people: intellectual (36%), psychiatric (15%) and physical disabilities (11%). Notably, Aboriginal people tend to experience more multiple disabilities (46%) than non-Indigenous people (34%). Other conditions are important in regards to chronic disability such as congenital causes, post injury conditions, depression and other mental health problems, dementia and stroke.

Government policy

Governance and service distribution of aged and disability care is varied and at times, complex. Government and non government bodies distribute packages and services according to availability, inclusion criteria and funding streams. The following section will aim to summarise current policy direction and strategies adopted for aged and disability care

Disability and aged care services are an important priority for national Indigenous policy development[13].The current WA Department of Health[14] plan to improve rural and remote health

services in Indigenous and non Indigenous sectors includes strengthening relationships and policies surrounding aged and disability care, expanding the Home and Community Care (HACC) program and redesigning the community care service model. The Department are seeking to boost the numbers of Aboriginal service users as well as improving current initiatives such as the Council of Australian Governments Long Stay for Older Patients (COAG LSOP) and current Aged Care Assessment (ACAT) program. The COAG LSOP initiative aims to improve care, preventing premature or avoidable hospital admissions and minimising the risk of functional decline. At the federal level, the Department of Health and Ageing[15] goals include improvements in service collaboration, quality and access in community care/health care. The Department also seeks to align and merge packages and streamline contracts across the nation[15]. The Aboriginal Disability Network[16] suggest that service delivery and structure is reflective of non Indigenous Australians, which may not fit to the needs of Aboriginal people with disabilities. Consultation and collaboration between agencies and communities is viewed as essential, and without doing so can perpetuate disadvantage[16]. It has been suggested that the responsibilities and accountability of state and federal bodies and non-governmental organizations (NGO) responsible for care are often unclear due to varying funding streams and governance.

The National Partnership Agreement on Remote Service Delivery[4], signed by the Council of Australian Governments (COAG) has set the following objectives for remote service delivery in Aboriginal communities to close the gap on Indigenous disadvantage (p.5-6):

(a) improve the access of Indigenous families to a full range of suitable and culturally inclusive services;

(b) raise the standard and range of services delivered to Indigenous families to be broadly consistent with those provided to other Australians in similar sized and located communities;

 (c) improve the level of governance and leadership within Indigenous communities and Indigenous community organisations;

(d) provide simpler access and better coordinated government services for Indigenous people in identified communities;

(e) increase economic and social participation wherever possible, and promote personal responsibility, engagement and behaviours consistent with positive social norms.

Another key objective of the COAG agreement to build Indigenous and service capacity is to increase non-government, corporate and philanthropic engagement in remote service delivery in Aboriginal communities[4].

Community services
Community care services throughout Australia are widespread and varied, ranging from small non government packages or outreach services to state, territory and federal government funded care.

Services and packages have developed and adapted to changing needs, and community care service delivery takes differing approaches in different regions. Home and Community Care (HACC) fund government and non-government organisations to deliver flexible services to the frail aged and people of all ages with disabilities, and their caregivers[3]. Carer support stems from National Respite for Carers (NRCP) and a variety of other bodies such as Carer's Australia, Red Cross and Disability Services Commission (DSC) [11].

Existing disability services are currently funded by the Commonwealth State-Territory Disability Agreement (CSTDA). Planning, policy and management of services is under the jurisdiction of the federal government and the state and territory bodies who are responsible for accommodation and community support, community access and respite. The Disability Services Commission is currently the largest disability organisation. There are a variety of non-government organisations specialising in specific areas of disability that provide assistance, education, respite and care to those living with a disability. Some confusion over state, federal and territory responsibility has been expressed by agencies unsure of governance and coverage areas[17]. Current data from the most recent census indicates that there were approximately 7,182 Indigenous CSTDA funded service users; or 3% of all service users[3]. Indigenous people versus non Indigenous people utilised more community services (53%:42%), accommodation (20%:13%) and less of employment (24%:38%) and community access services (20%:23%)[3]. O'Neill, Kirov & Thomson [18] suggest one out of three people with a disability do not access disability services.

Service gaps
Service providers have made many efforts to provide quality services to a diverse population. Despite this, a plethora of sources have identified ongoing gaps that impact upon service usage,

access and quality. Several key themes have been identified that present as significant areas for improvement in services, which will be discussed.

Cultural security is a concept that encompasses more than awareness of knowledge of cultural principals [19.] Cultural security also includes putting this knowledge into place, behaving in a culturally appropriate manner and providing services that reflect cultural preferences and best practice [19, 20]. Services and programs must be "accessible, responsive and accountable to those with the greatest needs in the community" [19] (p.1). Accommodating family, awareness of local structure and practicing culturally secure care is paramount to positive health outcomes and health and well being [21,22].

Current service frameworks, which are of western origin, may not be appropriate for Aboriginal health care[23]. Service models can clash with Aboriginal identity including culturally inappropriate behaviours and differences in belief systems that affect health care[24]. Shame can also result when people are forced to act in ways that are not sanctioned by the community or which can conflict with spiritual obligations, often resulting in the discontinuation of treatment and poorer health outcomes for the individual[22]. Many services were developed through mainstream urban frameworks, models which are unsustainable in rural and remote locations [24]. Perceptions of mainstream services may not always be favourable due to associations with culturally inappropriate care[18]. The need for culturally competent services is ongoing [25,26]. This includes accountability and responsibility, genuine collaborative partnerships and respect for culture[6, 27, 28]. Research has strongly linked genuine community development approaches and principles with positive health outcomes, including increased access to services, patient satisfaction and lowering of preventable hospital admissions[6, 23, 28]. Participatory processes are essential in delivering health care[27] and can "foster individual, small group community empowerment, which contributes to improved individual and collective health status"[29] (p.152). This includes communities identifying issues (as well as their solutions), and being involved in all stages of decision making, power sharing, management and delivery of services[6, 29]. A number of factors are integral in delivering culturally appropriate services for Indigenous people.

Staying on land and country is an inextricable and integral aspect for Aboriginal people[16,30]. If clients are surrounded by a familiar environment, their family and land, it can give them safety and comfort as well as opportunities for passing on sacred knowledge and participating in

community. During death and dying, staying in and on country allows the spirit to return to the land and for individuals to stay connected to family[30,31].

Concerns regarding a lack of understanding about health conditions, ageing and disability have been raised by several studies, highlighting the need for <u>education and training</u> for carers, families, communities and health services alike[32-34] . Usage of language services and culturally appropriate education materials such as booklets, videos and training aids developed locally by community, as well as one to one training in Indigenous languages have proven to be popular and effective[35], yet underused[36]. In addition, gaps in knowledge of entitlements, services and advocacy appear in many groups[18]. Alzheimer's Australia NT[33] noted a lack of specialist training in relation to dementia for practitioners, allied health staff as well as the community.

<u>Indigenous employment</u> continues to be an area with great potential for improvement in rural and remote communities[6, 27, 35]. High staff turnover, lack of professional support, less opportunity for training and development and lack of professional supervision result in short tenures of health and community care professionals[18]. Several sources have strongly suggested the need for an increase in Indigenous paid carers and stronger support networks[11, 18, 33]. Flaxman, Muir & Oprea[21] also add that once key Aboriginal staff were found, they were "critical to the success of the project" (pp.29).

Current service models are lacking in necessary <u>infrastructure</u>, available workers and funding to provide appropriate services, with some services providing meals only[33]. Infrastructure within the community in many cases impedes complete access to areas for those with a disability or physical impairment. Mobility outdoors is considerably reduced in the wet season and lack of appropriate paths and rails can prevent participation in community[18, 24]. <u>Transport is</u> a significant issue in remote communities being the most common barrier to accessing services[24, 37]. Access to a vehicle can be limited and the costs associated may be considered too high. Rain and flood waters can impede access of services entering the community, as well as those trying to exit[18]. This can directly impact all primary health areas as well as access to home help, respite services or therapy[18] or simple tasks such as attending appointments, picking up medication or mail and attending specialist services[38].

Aboriginal people have disproportionately lower rates of usage for <u>respite care</u> despite a great need[17]. Respite and culturally appropriate activities are considered essential for carer and client wellbeing[17]. Interventions to reduce carer stress include education, training to improve coping skills, support groups, counselling and access to appropriate and timely respite services[39, 40]. However, Alzheimer's Australia[41] reported that up to 58% of families had issues relating to these services including lack of culturally appropriate activities, a paucity of services and facilities, little social support as well services being away from home and country. Service providers, families, carers and clients have expressed a need for culturally appropriate activities such as fishing, camping and sitting around a fire with family and friends[24, 41]. Senior[24] highlighted that cultural activities can have little meaning if clients are not on country. Lack of feedback to these services was attributed to a fear of losing what little help they accessed. Aboriginal people are twice as likely as non Indigenous people to be carers, and often care for more than one relative[3, 17]. Recent reports indicate Aboriginal carers had difficulties in accessing the services or received services that were substandard or culturally inappropriate[42,43]. Caring for the carer is of importance, as carer well being is linked to that of their family member[44].

Current care initiatives

While a number of gaps in services have been identified, it is important to acknowledge the many initiatives and principles of service delivery which have a positive impact upon health. There are several shared characteristics which lead to increase in usage of health care and provide effective, quality support in partnership with communities. Services that were flexible, culturally appropriate, and collaborative and responded to the needs of the individuals were highly utilised[45, 31] Sustainable health care must incorporate a strong foundation of communication, consultation and cultural safety[46]. Models are required to be flexible in their approach, providing culturally appropriate care and support for carers and their families[33].

Shanley[47] maintains that flexibility in both the response to the needs and internal service organization will increase service usage and access. Examples of this are culturally appropriate services encompassing day and night respite, day centres, social outings and holiday programs. In addition to this, extended hours, emergency care and mobile respite care would be beneficial to clients, carers and their families. A current program that is said to be both popular and

successful is the Remote Respite Camp Program (or "Troopy Respite Program") which provides unique and culturally appropriate respite care and assistance[48].

Flaxman, Muir & Oprea[21], emphasise several key elements crucial for optimal service provision in Aboriginal communities that services "be integrated and holistic, and also that they coordinate, share knowledge and refer clients between services" (p. 13). Other literature has highlighted the importance of collaboration, coordination and holism of services in rural and remote communities with the need to multi skill[15]. This could include usage of multiple funding streams with genuine acceptance by multiple bureaucratic partners and simplification of direct line management structures. These partnerships have been stated as future strategies for the WA Department of Health[14, 49] in aged care and disability services.

Leisure buddies, culturally appropriate activities as well as education and support for carers, families, staff and communities, coupled with an increased collaboration between services may provide optimal care and respite[47, 50]. The Aboriginal Disability Network[16] suggest the value of having state, federal and NGO funded advocacy and representative organisations for people with disabilities, as well as monitoring and evaluation of current disability services.

An example of a collaborative and culturally secure model of care operating in a remote area is the Katherine West Health Board[51-53]. As a result of community consultation and service providers, the health board was founded to provide culturally secure, quality care to Aboriginal communities residing in the 162,000 sq km Katherine West region. The Aboriginal controlled, managed and facilitated organisation aims to provide a high quality of collaborative care, reducing the "silo effect" of resources and power into an adaptable and information sharing organisation[53].

Wakerman[51] succinctly encapsulates the common "essentials" for remote health models. These are adequate funding, consultation and participation, shared information systems, collaboration and leadership. Wakerman[51] also emphasises the need to conduct quality reviewing and evaluation of such models and comparative studies.

Conclusion

This literature review has examined some of the current models of care, policies and promising initiatives operating in Australia. Services thus far have made many efforts, some of them successful, in providing health care to Aboriginal communities. Key principles in the positive initiatives reviewed in this paper were flexibility in service delivery and frameworks, genuine collaboration and consultation with communities, utilising culturally safe frameworks of practice, empowerment, and education and employment strategies.

Section Two: Unmet needs study

Introduction

The authors have been involved in consultative ageing research with Kimberley communities since 2003. The first research study involved the development and validation of the Kimberley Indigenous Cognitive Assessment tool, a cognitive assessment tool that is now widely utilised within remote and rural areas of Australia. This was followed by a study which determined the high prevalence of dementia in Indigenous Australians aged over 45 years (12.4%). Despite the high burden of dementia affecting Indigenous communities there was a paucity of information on the unmet needs of people living with dementia living in remote Aboriginal communities and ways to effectively and equitably deliver community care to this group. In order to determine the unmet needs of Indigenous Australians living with dementia, qualitative research was conducted in the Kimberley region of Western Australia from 2007-2009.

Methodology

A steering committee comprising of past and present Aboriginal caregivers, remote community representatives, and service providers was formed to advise and guide the research project. An extensive scoping study was conducted through a mix of phone and face-to-face interviews with Kimberley service providers to Aboriginal people living with dementia. Face-to-face in-depth interviews were then conducted with Aboriginal caregivers and remote Aboriginal community care staff. Finally focus groups were held, drawing on the themes determined through the in-depth interviews, to assist with model development.

Results

Kimberley service providers (n=42), caregivers of Aboriginal people with dementia (n=16) and remote Aboriginal community-based aged care workers (n=15) were interviewed in six remote Aboriginal communities and two towns. The majority of the caregivers were female (n=12). Half of the caregivers were aged between 40 to 60 years and 30% aged between 60 to 80 years (n=5). Three carers were aged less than 40 years (20%). Two-thirds of Aboriginal community-based aged care workers were female (n=10) and one-third were male (n=5). Three focus groups were held with remote community councils, one with aged care service providers and one with the steering committee which consisted of community members, caregivers and service providers.

The results from the interviews indicated many areas of major unmet needs in the Kimberley region for people living with dementia. The responses from service providers and caregivers of people living with dementia are grouped into seven broad themes outlined below. These include caregiver role, perspectives of dementia, community-based and culturally secure care, workforce, training and development, issues affecting remote communities, and service issues.

Theme one: Caregiver role

Participants placed a high value in looking after their older community members. They also expressed experiencing a high level of carer burden through providing care in difficult circumstances, and have additional caregiver roles such as with children and other family members. Carers indicated that family are instrumental in providing support as well as a preference for "countrymen" to assist in the care giving role. The collaborative and sharing nature of communities was reflected strongly, for example pooling resources such as food.

Yeah I've got four kids of my own plus um one of my sister's child I'm looking after as well. It's a big job, it is yeah trying to work and juggle family at the same time…all of them at school ahem one's at home and looking after her is like four kids in one because she's like a big kid herself. Um and it's very hard. (Carer 4)

Some other families do, they come and help, help me with her. If, but, if we don't have tucker, then some other families bring her food. (Carer 1)

Carers indicated a need for greater levels of support from the community and service providers. Cultural and family responsibility was a key reason given by caregivers for how they came to be caring for a person with dementia in the community, as well as the importance of the continuing contribution of the older person to cultural values of the community. Carers also highlighted the need for the person receiving care to stay where they are happiest, with their family on country.

Yeah and often they are the glue that holds that family together and they are relied upon and if that person passes everything just goes pear shaped so you know, the family starts to break down…because that one elderly person is often holding that family together. (Carer 5)

Even for the little kids they learn a lot of her as well; yeah it's good for her sometimes. She teaches in languages. Words right and wrong how to respect others, she does a lot of things. (Carer 4)

This information from caregivers did not support the stereotyped views of some service providers who presumed that the majority of caregivers were more interested in receiving government payments than providing care.

When discussing carer payments that people were happy to put up their hand, but that in terms of actual care people weren't so willing. (Service provider 18)

Theme two: Perspectives of dementia

Gaining an understanding of how caregivers and community workers view dementia may assist in the provision of quality care and education. Caregivers spoke about how they first noticed that their family member had dementia, such as forgetting where things are kept and people's names, and the difficulties of behavioural changes. The causes of dementia given by caregivers and community workers included head injury, lack of family visits and ageing.

When you get to that certain age they accept it ah finish you know…err there'll be one to say oh I fell off the horse long time. (Carer 9)

Oh, getting too old must be for them, looking at memory and not enough family coming up to see them and they looking for Aboriginal family, losing them memory and getting old too. (Community worker 1)

But your brain wrong …memory…forget everybody. (Carer 3)

Ah talking like um silly and…yeah walk around everywhere sometimes he used to get lost. (Carer 12)

There was interest in learning more about dementia. This is discussed further in theme five.

Theme three: Community and culturally centred care

Theme three outlines the need for community and culturally-centred care. This includes the importance of genuine collaboration, community involvement at all levels, and respect of the needs of the clients and families. Caregivers, service providers and community workers felt strongly that dementia initiatives needed to engage the community at all levels to be successful.

They should be working in closer like err well it should be a two way thing community and the service provider and the carer and the person that's being cared for and the whole family in general that sort of thing gotta be sit down and worked out together. (Carer 41)

Any project / initiative needs to be community driven / input from the community. Must be culturally informed, as only way that project will work. Must involve family (of those with dementia) and the community and the council in the project. (Service provider 41)

Countrymen could also assist the agencies coming in by identifying what services they want in their community and how to implement those programs. (Community worker 10)

The importance of the person with dementia being able to stay in the community close to family and country was discussed, and the benefits this has on their memory and general health.

Keep them home with their own mob families you know…Close where they can remember things every time we repeat things to them you know…They start remembering things then…Properly you know but when they go with Kartiyas they just… Forget. (Carer 8)

Well I am just saying like that's another reason for this thing I think with elderly people is keeping them in Country. You know even though they are losing their mind in terms of their memory and lose concept of who's who and whatever, it is still important for them to feel connected to their country and taking them away like I am sure that they want to die and pass in their country. You know that's their spirituality that's their connection. (Community worker 5)

Service providers and caregivers recognised that community members are reluctant to go to town based residential care as it is seen as a place where people are sent to die and there is no family nearby.

Also that sometimes people will associate respite at a hostel or frail aged place as a place to die, and won't want to send person there. (Service provider 35)

Because she said to me 'they want to just drop me of there so I can die', so she has a fear of Numbala Nunga and Frail Aged she says she just likes to visit...but she will never stay there. She says 'if I go to them places I'll die.' So I think with the family environment, the old girl loved it. (Carer 5)

See when they at frail aged they feel lonely no one...nobody's there nobody to visit them family there in town but they don't go into visit him that's when they...they feel upset and they want to be amongst their own people and going out fishing they like to go out too. (Carer 11)

The need for culturally safe activities was discussed, with caregivers providing some recommendations for appropriate activities. The need for consultation and communication was again reflected in carers' responses.

But for activities and that, it should be something that should be worked out between the person and the carer and the community where they looking at the environment on where they live. (Carer 14)

You can't just keep her around the place that's what I've been telling them mob over there oh you gonna take him shopping and, and fishing or hunting and keep her mind you know working all the time. (Carer 9)

Theme four: Workforce

Aboriginal staff members were viewed as essential for providing culturally appropriate and optimal care for Aboriginal people. In addition, participants felt that staff must be trusted and recognized by the community for carers to be comfortable with leaving a loved one in their care.

They need some Aboriginal people working in HACC to show them where the places are to take out for activities. Yeah no Aboriginal people which is funny..not funny but I think it's really silly because the majority of clients is Aboriginal people. (Carer 4)

There needs to be more staff in the community itself... Noted programs set up, too many white faces. (Service provider 39)

It's getting the appropriate person or persons to, to take on that type of role you know yeah. That's right then you'd have sort of have a little trial run through the day. Not that I don't think that they'd be capable because I mean they wouldn't just go and recommend just anybody willy ninny. (Carer 6)

Sometime when they see stranger whether it be white or black person they…wanna know who it is otherwise they get shame. (Carer 9)

Caregivers, service providers and community workers recognised the problems of shortages and high turnover of staff in the region and its negative impact on other staff and the delivery of care. It was discussed that staff shortages led to a lack of support for other staff which often resulted in burnout. A lack of housing in the region, particularly in remote towns and communities, was seen by many as a barrier to finding and retaining external staff. The inequity of only higher paid staff receiving an accommodation allowance was also discussed. Other issues such as low pay and undervalued positions as well as domestic issues impacted upon the community, families, clients, carers and staff.

They have problems with staff too, see it keeps changing you know… so I guess you train them up and then um they go. (Carer 7)

There is a high turnover of staff as people get burnt out. 2 also noted that a lot of support is also needed for the remote HACC coordinators as burnout is common (Service provider 2)

Also noted that jealousy is a very real problem and prevents a lot of women from becoming workers. .. The young woman did not turn up, as there were issues with her partner jealousing her. (Service provider 9)

Theme five: Training and development

Theme five captures the need for ongoing training and development. A constant theme that emerged in the interviews was the importance of cultural training for service providers and external community care staff. An example was given of many non Aboriginal service providers being disrespectful to community members by trying to act as though they were Aboriginal, rather than being themselves. As well as this, the term "being judged" or "not judging" was also common in discussions.

First they need to do a cultural awareness, for a start. They need to learn a few protocols Because just in um, what happens with the different clans and you know groups that we have got cause I know that a lot of them feel disrespected when they don't. (Carer 5)

They should have some basic understanding of Aboriginal culture and respect the way they live and not be judgmental. Respect areas that have cultural significance, Law grounds men and women. (Community worker 10)

Ah, a lot of the girls or even the Kartiyas that do come here, a lot of them end up - oh how can I say [laugh] a lot of them end up like they're Aboriginal and they're not. Do you know what I mean? Now, you know they are acting, dressing everything you know what I mean? Talking so that's ah… if only most of them knew that that's disrespectful. Do you know what I mean? Go in there as yourself and you'll get on – and they'll teach you! (Carer 5)

It was noted that service providers, caregivers and community workers would benefit from training and education particularly in relation to dementia, elder abuse, the Kimberley Indigenous Cognitive Assessment (KICA) and what services are available to support a person with dementia and their families.

Well there should be more information given out to the families and that because not too many people know that there is help available they just government mob just keep it all within the office. I don't know who they get as field staff and that to take the information out to um educate the people on just awareness of what support is there available for people. (Carer 14)

34 (service provider) noted that she sees dementia as a bit of a grey area (in her knowledge) and would like to know more about dementia, and that family need to also be more aware, know more about dementia. (Service provider 34).

Generally there was poor understanding of dementia amongst the care workers (Service provider 6)

Training more staff regionally to use the KICA for assessments (with a focus on GP's). (Service provider 1)

Knowing what the signs are if someone is been abused (Service provider 2)

Theme six: Issues affecting remote communities

Carers and service providers spoke about the issues affecting remote communities, the distance to main services and competing priorities of need. A lack of community housing can lead to caregivers being unable to continuing to care for a person with dementia, resulting in admissions to town based residential care. Overcrowding also affected the success of health professionals' recommendations.

All the kids and we bin bring them back here so we've bin all living at camp but it was too much crowded you know… it was crowded so we couldn't stay there. (Interviewer 'so now she's over there in that frail aged'), 'yeah.' (Community worker 8)

14 gave the following example of trying to give practical support, he had recommended to keep floor surface dry (overcrowded house, big mob of people showering all the time and kids etc – very difficult to maintain), trying to keep the floors free of obstacles at night time to avoid falls or tripping when wandering (people sleeping on floor – this was not often possible.) (Service provider 14)

High living costs in remote areas, particularly for food and transport, is affecting the ability of families to care for a person with dementia. With families struggling to pay for food the older person may at times miss out on a nutritious meal or a meal altogether.

25 noted the financial hardship of clients, how everything is so expensive in the Kimberley and that pensions are inadequate. Particularly for people who struggle to budget and get by. (Service provider 25)

They need to be fed proper food…to have enough…whatever they got at home what's left over somebody else come to their house and say who for this food…and they can't remember sometime if they've had a meal (Carer 9)

A lack of public transport, access to vehicles and the high cost of fuel affect the affect the ability of older people in remote communities to access health and community services, to take part in activities and to visit family and friends.

A lot of people don't have transport. Their own transport. (Carer 14)

You know when they bring them people out now for pensioner they should drop them with their family…And then that family can take them to the pensioner quarters when he ready time… Sit down with the family all day righto. (Carer 8)

The issue of elder abuse was discussed with service providers and community workers requesting training and recommending community education on the issue. One service provider suggested alcohol and drug related problems in communities may also lead to elder abuse.

The other thing that we also see is elder abuse….In the community. So just making people more aware that that does go on and that does happen and how we can you know recognise it because a lot of people don't talk about it…And it happens in Aboriginal families and non-Aboriginal families…And that may simply be neglect, not changing their nappy, not making sure they are showered, not giving them a good feed. So they're all forms of elder abuse and it can be emotions as well so it…and demanding money, taking the nanna key card. I mean that's all forms of elder abuse. So, I think more community awareness about how can we look after our grannies better, and how can we prevent them from been abused. (Community worker 5)

Minimise alcohol, gunja, domestic violence – as even though demented person may have never been a substance abuse, they are more than likely impacted on by those who do, i.e. son who bullies, neighbours who trash place when drinking. 30 stated that all of these factors do not cause the dementia, but certainly aggravate the condition / symptoms. (Service provider 30)

Theme seven: Service issues

Key areas discussed by participants were the need for communication and coordination of services and flexibility in service provision. Other issues that were highlighted were the geographical distance of services from communities, a lack of interpreter usage, the need to improve clinical pathways and protocols, and a shortage of appropriate services.

The first key service issue emphasised by caregivers, service providers and community workers was the real need for improved communication and coordination between service providers, and between service providers, communities and caregivers. It was stated that this lack of co-ordination and client advocacy is impacting on the ability of the person with dementia to remain living in the community safely.

People (service providers) visiting the community and not informing the clinic – if we can't work with each other than how are we going to work with the community, noted frustration of this. Agencies in... don't communicate very well – and there are only five main services. Have tried to have regular meeting etc, but never works out. (Service provider 31)

They should be working in closer like err well it should be a two way thing community and the service provider and the carer and the person that's being cared for and the whole family in general that sort of thing gotta be sit down and worked out together. (Carer 14)

There is also difficulty in communication between service providers and family carers. Service providers have a lack of awareness of what the family carers needs are. (Service provider 3)

I was waiting on Homeswest to install some bars since last year. So they still haven't done it. I'd be ringing them up boy or getting HACC and aged care mob to do it to ring up about it and the OT and the physio they find it really hard they reckon and then it would take eighteen months. (Carer 4)

For people to stay for longer in community there needs to be better liaison, which would result in a smoother ride for the client and more of an understanding. (Service provider 16)

Some of the attitudes portrayed by service providers interviewed were discriminatory or defeatist, which may affect the quality of services that they are delivering to people living in remote Aboriginal communities. The discriminatory attitude of the general community towards remote Aboriginal community members has also impacted on client care.

There are huge weaknesses in community…how do you pass on the values of empowerment, responsibility if you can't give people a book. Have to use incidental chances. (Service provider 2)

Family don't seem to give a shit, no family based carer (Service provider 28)

(Service provider 25) Gave an example of Homeswest meeting where three letters had been written/ were presented that were anti the renal clients being able to access housing in town, some have a prejudice against those not from Broome, from remote communities or out of town.

A key strength of services was their ability to make service provision flexible to meet the needs of the community. However the need for generalist health service to be less discriminatory about the aged and more actively involved in providing quality services to this group was also discussed.

08 noted strengths during conversation in relation to the flexibility of the program, to be able to tailor to remote needs. (Service provider 8)

Health care services in general need to consider aged care to be the norm and not a specialist field or someone else's responsibility. Should be a part of standard, normal practice. Health care services need to change their focus from age, to that of function, to not discriminate against older persons or young people with disability. (Service provider 3)

The distance between towns and remote communities affects the ability of service providers to provide quality care to people living in these regions.

Distances of remote clients, don't have adequate support for either worker or client. Because of the distances education with dementia for staff and family is important. (Service provider 16)

Geographic sparseness, which has an effect on having to establish rapport with people in remote communities. (Service provider 19)

The services are delivered so infrequently that it is hard to say what is done well. (Service provider 41)

Service providers stated that interpreter use was lacking in the health and community care setting.

Noted the Anunga rules which bind police / lawyers etc to ensure that interpreters are available, that the person can understand questions. 20 thought that there should be a similar set of laws for health settings, gave example of people in hospital not understanding medications etc and how information is not passed on the client. Thus there is seldom informed consent. (Service provider 20)

Need to use interpreters more as sure that patients just say yes a lot of the time and won't understand. (Service provider 31)

Clinicians highlighted the need for clinical pathways and protocols for dementia in the Kimberley region. An example of this is the lack of dementia guidelines has lead to inappropriate referrals. It was also stated that the lack of guidelines has lead to people with dementia not being diagnosed and missing out on support services.

There are currently no agreed upon best care practices that all health professionals at all services (NGO / Govt) use (for dementia). That there are no clear pathways for best care leads to inappropriate referrals, or missed referrals. (Service provider 3)

There are no strong protocols or clinical pathways to manage dementia (36 noted that these existed for hypertension), surmising again that there were no GP pathways. (Service provider 36)

They probably die before been diagnosed or accessing services (Service provider 20)

Service providers were concerned about the lack of aged care specialists based in the region and the infrequency of geriatrician and psycho geriatrician visits to the Kimberley.

More geriatrician / psycho geriatrician visits [are needed] (Service provider 1)

Some talk on absence of psycho geriatrician, and how there could be increased access to these specialists if people (e.g. nurse in remote clinic) were more assertive in identifying that is what is needed, and that they can use the videoconferencing facility (e.g. in Balgo) to link up with specialists based in Perth or metro areas. (Service provider 7)

Participants reported that community care services for people with dementia were lacking, leading to poor outcomes for people with dementia living in remote communities.

There is nothing to refer old people to in remote communities. Remote HACC is often not working. (Service provider 21)

Noted that the community HACC used to provide meals but that this no longer happens. (Service provider 28)

04 explained that in Looma, which was struggling a little with aged care service provision, that for a long time the older people who chuck in $5 a day for their meals were only been fed frankfurts as this is cheap and easy. (Service provider 4)

Case from community, an older demented lady living very happily at home, immobile, in bed, surrounded by 4/5 dogs, shit, rubbish. People let her stay in pigsty as to take her out would have caused immense unhappiness. Until finally, health services had to step in. This could have been eased if there had of been someone there earlier on in the older ladies life to encourage her to get out of bed each day etc, and that this would have eased the pace of the deterioration. (Service provider 30)

Caregivers of people with dementia frequently mentioned the lack of information and support for available to them. A paucity of activities and respite time were key issues for caregivers.

But, um I reckon there should be more information and more working with the family because there's nothing here. (Carer 5)

Nothing we don't get help from nobody we just help each other I suppose because we still have that independence as well but, that's just not the point sometimes it's good to have that little bit of help even if it's moral support (Carer 14)

The carer and the family in who they caring for to um assist them just by little day or overnight activities camping trips or like take them down the beach fishing or camp out overnight that sort of thing those old people love that kind they mightn't be able to walk but even just to sit down on the beach some of them just love it, it builds their morale up too make them feel good and gives that bit of but even though when you do that you still need someone to give that extra support to the carer as well because so that there's a bit of balance for the time for the person the client having their own time as well as the carer having a little bit of time out for themselves as well. (Carer 14).

Conclusion

The results indicate a number of unmet needs for people living with dementia in remote communities, their caregivers and service providers in the Kimberley region. The key unmet areas identified by the extensive interviews were reflected in the need for genuine community consultation, service coordination and communication, community-based services, culturally secure services, Aboriginal workforce with local guidance and support, and education and training.

Section three: Model of Care development and trial

Introduction

This section will present the development of the model and the final evaluation results of the model of care. These results will be supplemented by an independent evaluation completed by Rhonda Murphy of Yarmintali Consultancy, which will be available separately on www.wacha.org.au. The primary objectives of the evaluations are to determine if the proposed model meets the unmet needs of the target population including genuine community consultation, service coordination and communication, community based services, culturally secure services, Aboriginal workforce with local guidance and support, and education and training. The 12 month financial report was not available from Kimberley Aged and Community Services (the project fund holder) at the time of writing and is to be lodged by KACS on 30th September 2010.

Methods

Quantitative data

Data are based on tick sheet reports (see Appendix VI and VII) and qualitative data gained from staff journals as well as feedback forms from clients and services. Tick sheets are a weekly summary of service usage, type and number of clients accessed with remote HACC permission. The service provision "tick sheets" assessed the growth and development of the service in a measurable format. Staff placed a tick beside the type of service and name of client, carer or community group. Weekly tick sheets were entered into a spreadsheet and totalled into four weekly brackets, with the aim of assessing the consistency and measured growth or decrease of services. Additional research tick sheets were created to ensure all activities were measured such as advocacy; community, client and caregiver education; art, camping, fishing, hunting, BBQ picnics and day trips.

Qualitative data

Qualitative data was collected from staff diaries, Feedback/Service Improvement forms from clients and carers (see Appendix I) as well as testimonials from services and the Looma community (see appendix II-IV). The staff kept dairies on a daily basis detailing services

provided. These diaries complemented the tick sheets by providing a greater detail to the data such as communications with service providers, clients and families as well as details on activities such as hunting, fishing and town trips. Videos and photographs were also utilized to illustrate change. All photos are taken and used in this report are done so with permission.

The project was also independently evaluated by an external consultant, Rhonda Murphy from Yarmintali Consultancy at baseline, six months and twelve months. This external evaluation involved qualitative interviews with service providers and community members, and is separate from this report. The external evaluation can be accessed on www.wacha.org.au or by contacting Dina.Logiudice@mh.org.au.

Model development

Based on the literature review and the unmet needs determined by Aboriginal community members and Kimberley service providers a model of care was developed, with assistance from community focus groups, the Kimberley steering committee, experts in the field of Aboriginal education (including board member of Graham Polly Farmer Foundation) and health, and study investigators. During this process it became apparent that to be of benefit to a greater number of people and for the effective use of resources, the model of community care should aim to support a broader population than only those people living with dementia. In consultation with the community and service representatives the community care model was extended to encompass the frail aged, people with disabilities of all ages and people with mental illness living in remote Aboriginal communities and their caregivers with similar community care needs.

Following in-depth consultation with the six communities involved, Looma community was identified as the site for the twelve month pilot for three key reasons. Firstly, Looma had the highest proportion of their community members over the age of 45 years living in residential care away from their community out of the six communities and one town studied. Of the 62 people from Looma aged over 45 years, 15% were living in residential care.

Table 1. Residential care versus community status of Looma participants

	45-59 years	60-69 years	70-79 years	80+ years	Total
Residential care	1 (4%)	2 (13%)	2 (13%)	4 (57%)	9 (15%)
Community	24 (96%)	13 (87%)	13 (87%)	3 (43%)	53 (85%)
Total	25	15	15	7	62

Secondly, it is a 'typical' remote community which faces unmet needs and issues common to other communities in the region. Thirdly, there was interest from the community council who subsequently approved and gave their continuous support to the project. Looma Community is a remote Aboriginal community in the Kimberley region, approximately 120km south east of Derby, in Nyikina country. There are approximately 350 people residing in the community and the three main language groups residing in the community are Nyikina, Walmajarri and Mangala.

The Kimberley service providers and organisations approached were committed to being involved in the project. These included Looma Council, Kimberley Aged and Community Services, Disability Services Commission, Kimberley Population Health Unit (including Looma community clinic), Kimberley Mental Health and Drug Services, Indigenous Coordination Centre, Frontier Services, Kimberley Individual and Family Support Association and the Derby and Fitzroy Valley Health Service Allied Health team. The project was funded for a one year period by Home and Community Care, West Australian Country Health Service-Mental Health and Disability Services Commission.

Model of care details

The Looma pilot model supports and engages the Aboriginal community and service providers at all levels through formalising partnerships and streamlining service delivery.

Figure 1: Lungurra Ngoora Pilot Model
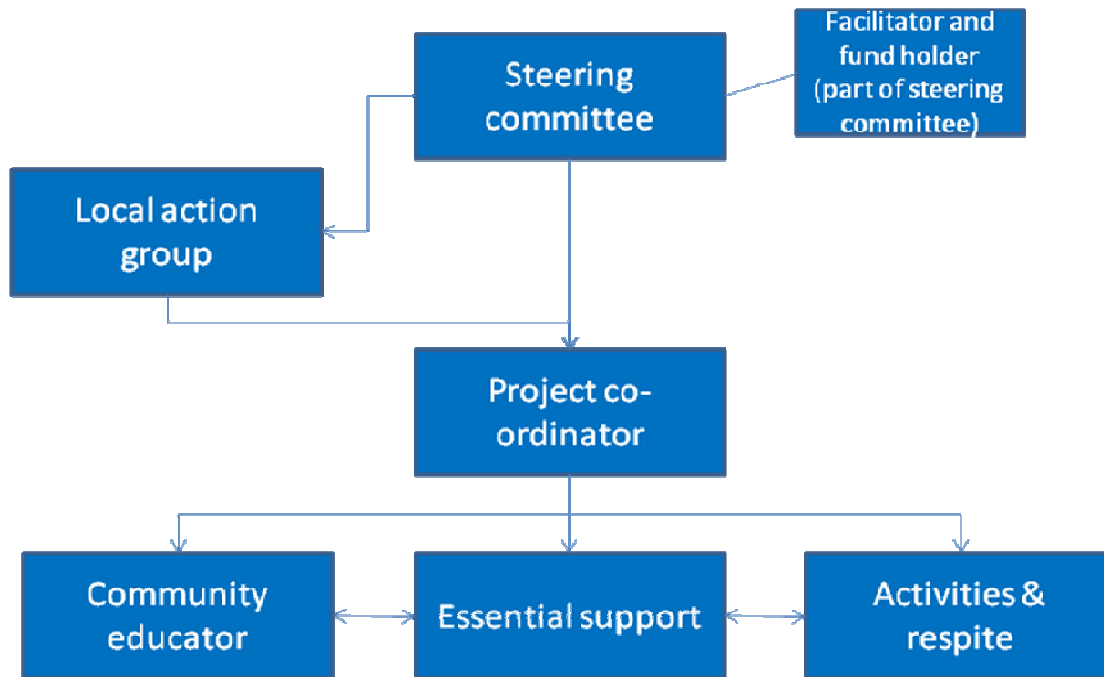
The steering committee provides resources and strategic management, and co-owns and co-funds the community care service. Shared objectives were established to guide the direction of services and service agreements were developed and signed. The committee consists of the community chairperson and a council member and the regional managers of organisations, and formalises partnerships between these organisations, and the organisations and the community. It also contains the independent facilitator of the project. During the trial the committee consisted of the Looma chairperson, Looma Council member, and regional managers of Kimberley Aged and Community Services (KACS) (including remote HACC, Community Aged Care Packages and Carers Respite Centre), Disability Services Commission (DSC), Kimberley Mental Health and Drug Services (KMHDS), Frontier Services, Kimberley Population Health Unit (KPHU), Indigenous Coordination Centre (ICC), Kimberley Individual Family Support Association (KIFSA) and University of Western Australia (UWA).

The facilitator role is essential to the model to streamline service delivery, enhance collaboration and cooperation between regional organisations and between the organisations and the community, and to provide impartial facilitation so that all interests are represented. It is recommended that if possible the facilitator is a non-government organisation (NGO) with a community development focus to work with the steering committee to breakdown the "silo" effect that can be a product of specialised services (such as aged care, mental health or disability) operating independently in remote communities. It also increases the involvement of local businesses which kindly donated goods regularly to the project. This is in line with current government policy to increase NGO and industry involvement in service delivery in Aboriginal communities. The facilitator also holds the project funds, providing regular financial reports to the steering committee and line manages the project coordinator.

The key qualities of a facilitator as presented to the steering committee are:
- A degree of independence to decrease silo effect of specialised services and focus on shared objectives.
- Experience in remote area project management and service delivery.
- Experience with and a genuine commitment to community consultation and capacity building.
- Potential to access and responsibly manage a wide range of funding sources.
- Ability to adopt a new flexible and creative approach to delivering care.
- Preferably a state or national reach to disseminate information for the benefit of other communities.

As no steering committee organisations were willing to take on the facilitator role at the beginning of the project trial, UWA was appointed facilitator for the first six months, with an agreement that another organisation be appointed and evaluated in this role in the final six months of the trial to enhance sustainability. Due to this temporary measure KACS took on the fund-holder role of the facilitator. In October 2009 the choice of facilitator for the final 6 months was tabled again to the steering committee, and two organisations were put forward, Frontier Services and ICC. The ICC was unable to take on the role. The community council approved Frontier Services and on 15th December 2009 Frontier Services were approved by the steering

committee. Frontier Services were evaluated in the role from 1st January to 30th June 2010. Rather than funds being transferred and held by the facilitator as per the model, KACS remained as fund-holder for the remainder of the trial.

The local action group is comprised of local service providers, a community representative and project staff. During the trial the local action group members consisted of the project staff and a client representative, the Derby remote area aged care co-ordinator, the Derby Aged Care Assessment staff member, Disability Services local area coordinator, the Mental Health Derby health professional, the Looma clinic Aboriginal Health Worker and a representative from Derby Allied Health. The members offered their expertise in key areas such as disabilities, aged care and mental health to project staff and provided resources, training and education as required. This group also acted as an accountability measure enabling project staff to regularly follow up on clients needs with local service providers. The group provided an opportunity to plan and co-ordinate the delivery of care to clients and appropriate decision making that reflected the community's wishes.

The project coordinator is based in the community. The coordinator liaises with service providers, clients and family members, ensuring a quality service. They manage the project on a day to day basis, supervising staff and facilitating training and administrative duties. The coordinator acts as an advocate for clients and carers, and assists with service delivery when required.

Community workers provide direct service delivery. Although they are given roles such as community educator, essential support and activities and respite officer, staff members move between these roles flexibly as required by project coordinator. The community workers consult with clients to provide culturally appropriate activities and respite, essential support such as meals, transport, laundry and personal care, and respond to the training or educational needs of the community and caregivers, and organise paid cultural training and interpreters for local services. One full-time position was funded through the joint project funds. The essential support worker was funded by a HACC conversion package applied for by Kimberley Aged and Community Services. Another position was funded through Job Creation packages.

Figure 2: Key target areas

Baseline results

At baseline the remote HACC provided meals and some laundry. There were many issues with service provision as highlighted in the unmet needs study "*There is nothing to refer old people to in remote communities. Remote HACC is often not working*" (Service provider 21). "*04 explained that in Looma, which was struggling a little with aged care service provision, that for a long time the older people who chuck in $5 a day for their meals were only been fed frankfurts as this is cheap and easy*" (Service provider 4). There were two HACC staff members (coordinator and general staff member) receiving top-up in addition to Community Development Employment Projects (CDEP). At baseline between 15.6.09 to12.7.09, eight HACC clients, who paid $120 per fortnight, received 140 services (meals, transport and home services. There was also one Disability Services client and three Kimberley Mental Health and Drug Service clients who were not receiving community care services. For further details an external baseline evaluation was completed by Rhonda Murphy and this is available on www.wacha.org.au.

Six month results

At December 25th, 2009, a total of 29 clients were provided with services. Of these individuals, 15 were aged care, two were under the mental health stream, two were under disability only, one was under aged care, disability and mental health, and nine people with disabilities were under DSC review. Their caregivers also accessed services. The ages of the clients range from 15-83. During the first six month period, two significant changes occurred for the community: a new CEO was appointed after a vacancy of some months and a new chairperson was appointed. Services increased from a baseline of140 services/month for 8 clients in June 2009 to 2003 services/month for 29 clients in December 2009. A total of 7836 services were delivered in the six month period. The six month report is available from www.wacha.org.au.

Final evaluation results

Service numbers have increased markedly from baseline. As stated by service providers in the scoping study in section II remote services are limited for people with disabling conditions across the region: *"The services are delivered so infrequently that it is hard to say what is done well"* (Service provider 41). *They probably die before been diagnosed or accessing services"* (Service provider 20).

At June 11, 2010, a total of 22 clients were provided with services. Of these individuals, 15 were under aged care only, one was under mental health, aged care, and disability, three were under mental health only, two were under disability only, and one person with a disability was under DSC review. Their caregivers also accessed services regularly. Services increased to a total of 2395 in the monthly period for a total of 22 clients. From 13.7.09-11.6.10, a total of 18,541 services were received by clients.

A greater depth of culturally appropriate services was offered and utilized, such as hunting, fishing, art, BBQ picnics, visiting country and visiting relatives in residential care (Total= n= 4057). Home Support services previously offered by HACC such as meals (n=8230), and home services such as laundry, social support and shopping were strengthened (n=2000). Advocacy (n=1303) and education (n=1131). The project staff worked closely with the community clinic to assist clients in accessing health care, particularly assisting in transport, referrals and nutrition.

Figure 3: Total Services (Baseline-17.05.10)

Total services (Baseline-12 months)
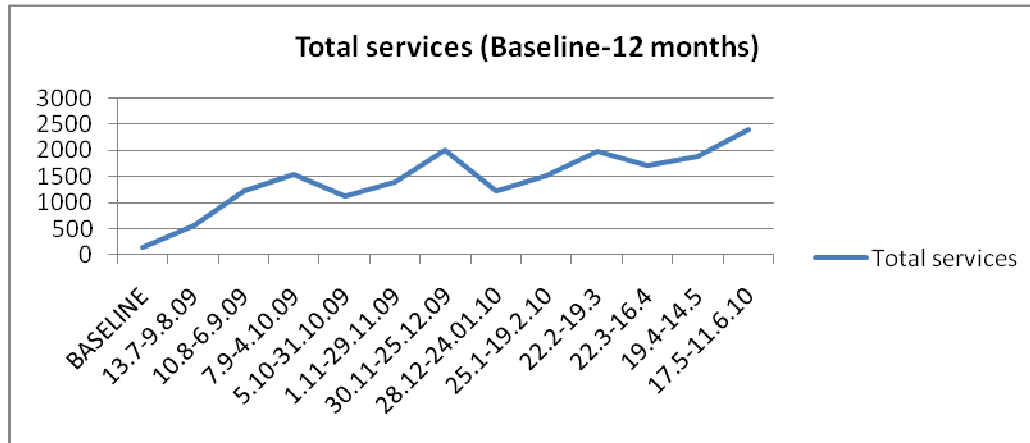
Table 2: Service usage and totals: Baseline-25.12.09

SERVICES	BASELINE	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	TOTAL SERVICES USED 13.7-25.12
HOME SERVICES TOTAL	21	58	164	274	167	50	400	1113
CLEANING	1	3	19	82	29	3	93	229
LAUNDRY	8	12	40	80	45	20	134	331
SHOPPING	2	10	17	34	24	8	80	173
SOCIAL SUPPORT	9	28	82	71	66	19	92	358
YARD/MAINTENANCE	1	5	6	7	3	0	1	22
TRANSPORT TOTAL	11	33	252	118	81	85	201	770
RESPITE/ACTIVITIES TOTAL	3	106	96	110	149	101	231	793
DAY CENTRE OUTINGS	3	16	6	16	3	30	76	147
CAMPING	0	6	0	1	3	0	0	10
FISHING	0	20	15	0	11	5	4	55
ART	0	16	0	0	2	0	8	26
GENERAL ACTIVITIES	0	32	54	92	96	26	86	386
OVERNIGHT TRIP	0	5	0	0	0	0	0	5
FOR CARER	0	0	1	0	0	0	0	1
BBQ/PICNIC	0	0	0	0	25	40	25	90
TOWN TRIP	0	11	9	0	4	0	30	54
HUNTING	0	0	11	1	5	0	2	19
PERSONAL CARE TOTAL	0	4	21	52	26	12	19	134
SHOWER	0	4	12	41	12	7	19	95
HAIR CUT/SHAVE	0	0	9	11	14	5	0	39
MEALS TOTAL	105	210	519	789	545	952	942	3957
BREAKFAST	0	0	0	0	2	0	28	30
LUNCH	105	210	404	395	277	490	499	2275
DINNER	0	0	115	394	266	462	415	1652
ADVOCACY TOTAL	0	92	95	126	100	154	115	682
FOLLOW UP ON SERVICES	0	37	46	41	48	50	19	241
DIRECTION TO SERVICES	0	20	0	2	1	4	4	31
REPRESENTATION	0	3	1	2	0	0	3	9
OTHER	0	32	52	103	51	100	89	427
EDUCATION TOTAL	0	52	64	77	48	42	95	378

AGED	0	3	0	0	1	0	5	9
DISABLED	0	3	0	4	1	0	4	12
MENTAL HEALTH	0	2	20	1	0	14	3	40
OTHER	0	44	0	30	46	0	83	203
COMMUNITY	0	0	44	42	0	28	0	114
HEALTH ASSISTANCE	0	0	0	6	3	0	0	9
TOTAL SERVICES	140	555	1211	1552	1119	1396	2003	7836
TOTAL CLIENTS	11	22	23	24	25	29	29	
TOTAL CLIENTS RECEIVING SERVICES	8	21	23	24	25	29	29	

Table 3: Service usage and totals 28.12.09-11.6.10

SERVICES	BASELINE	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10	TOTAL SERVICES USED 26.12.09-11.06.10	TOTAL SERVICES USED 13.7.09-11.6.10
HOME SERVICES TOTAL	21	86	158	148	125	176	194	887	2000
CLEANING	1	18	33	34	25	9	10	129	358
LAUNDRY	8	27	48	29	28	24	18	174	505
SHOPPING	2	17	20	32	16	26	35	146	319
SOCIAL SUPPORT	9	24	54	50	56	113	131	428	786
YARD/MAINTENANCE	1	0	3	3	0	4	0	10	32
TRANSPORT TOTAL	11	100	96	110	113	93	154	666	1436
RESPITE/ACTIVITIES TOTAL	3	400	317	676	359	572	940	3264	4057
RESPITE CARE: DAY CENTRE OUTINGS	3	70	102	108	114	100	157	651	798
RESPITE CARE: CAMPING	0	0	0	0	0	0	0	0	10
RESPITE CARE: FISHING	0	32	2	109	56	96	280	575	630
RESPITE CARE: ART	0	167	41	23	15	55	17	318	344
RESPITE CARE: GENERAL ACTIVITIES	0	85	81	88	51	80	50	435	626
RESPITE CARE: OVERNIGHT TRIP	0	0	0	0	0	1	0	1	6
RESPITE CARE: FOR CARER	0	1	0	0	0	1	0	2	3
RESPITE CARE: BBQ/PICNIC	0	0	84	116	35	95	233	563	653
RESPITE CARE: TOWN TRIP	0	24	7	200	88	144	216	679	733
RESPITE CARE: HUNTING	0	21	0	32	0	0	0	53	72
PERSONAL CARE TOTAL	0	11	25	18	22	42	29	147	281
PERSONAL CARE: SHOWER	0	8	21	16	21	25	19	110	205
PERSONAL CARE: HAIR CUT/SHAVE	0	3	4	2	1	17	10	37	76
MEALS TOTAL	105	436	675	836	903	769	654	4273	8230
MEALS: BREAKFAST	0	0	0	0	0	79	0	79	109
MEALS: LUNCH	105	436	543	418	452	345	327	2521	4796
MEALS: DINNER	0	0	132	418	451	345	327	1673	3325
ADVOCACY TOTAL	0	113	129	99	62	87	131	621	1303
ADVOCACY: FOLLOW UP ON SERVICES	0	23	6	2	3	5	5	44	285
ADVOCACY: DIRECTION TO SERVICES	0	6	29	18	3	1	3	60	91
ADVOCACY: RESPRESENTATION	0	2	30	0	3	0	5	40	49
ADVOCACY: OTHER	0	82	64	79	53	81	118	477	904
EDUCATION TOTAL	0	80	108	102	82	127	254	753	1131
EDUCATION: AGED	0	0	4	3	4	6	12	29	38
EDUCATION:DISABLED	0	0	4	3	3	9	11	30	42
EDUCATION: MENTAL HEALTH	0	1	69	31	32	58	105	296	336

EDUCATION: OTHER	0	74	25	64	15	16	5	199	402
EDUCATION: COMMUNITY	0	5	6	1	28	38	121	199	313
HEALTH ASSISTANCE	0	0	0	0	45	10	39	94	103
TOTAL SERVICES	140	1226	1508	1989	1711	1876	2395	10705	18541
TOTAL CLIENTS	11	29	29	30	30	30	22		
TOTAL CLIENTS RECEIVING SERVICES	8	29	29	30	30	24	22		

The following detailed results are presented under the target areas of home services, respite/activities, advocacy, transport, education, meals and health assistance, community consultation, service coordination and communication, workforce, accountability, and training and development.

Home services

Home services offered to clients included cleaning, shopping, laundry, social support and yard/home maintenance. Social support refers to such things as assistance with paying bills and reading out mail for the client. Home services varied in demand and provision throughout the twelve month period. The total number of services for respite offered increased from baseline (21) to six months (400) to twelve months (194). The total number of home services was 2000 (13.7.09-11.6.10)

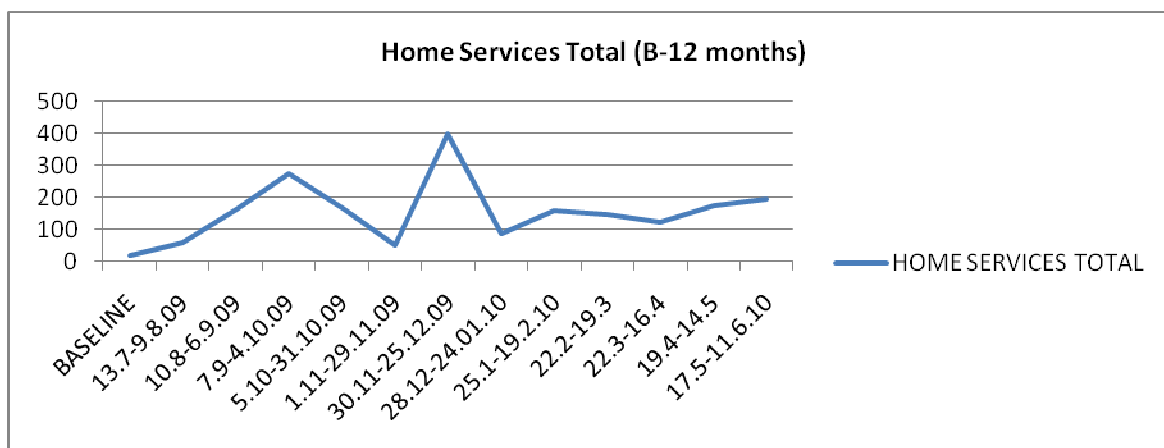Figure 4: Home Services (Baseline-12 months)

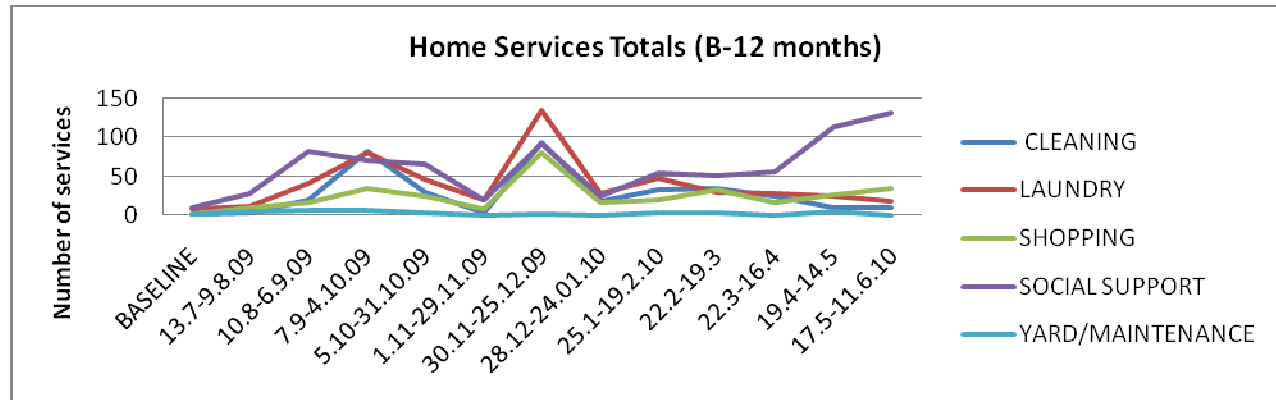Figure 5: Home Services Totals (Baseline- 12 months)

Table 4: Home Services Baseline-12 months

SERVICES	BASELINE	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10
HOME SERVICES TOTAL	21	58	164	274	167	50	400	86	158	148	125	176	194
CLEANING	1	3	19	82	29	3	93	18	33	34	25	9	10
LAUNDRY	8	12	40	80	45	20	134	27	48	29	28	24	18
SHOPPING	2	10	17	34	24	8	80	17	20	32	16	26	35
SOCIAL SUPPORT	9	28	82	71	66	19	92	24	54	50	56	113	131
YARD/MAINTENANCE	1	5	6	7	3	0	1	0	3	3	0	4	0

The dip in services from 1.11-29.11 (50) coincided with a period of high staff turnover and intensive education and training sessions that the staff attended. The spike of 400 at six months was prior to the Christmas period and a decrease occurred post Christmas at 86 services due to staff and client holidays. Staff assisted clients on an individual basis according to the needs and preferences of clients and families, sometimes collecting laundry and dropping it off, or assisting the person in their home or at the centre, depending on their abilities. As reflected at the six month period, of all the services, the two most in demand were social support (786) and laundry (505). Social support included assisting individuals with paying bills, home help and management as well as other areas identified by the client.

Figure 6: Home Services (13.7.09-11.06.10)
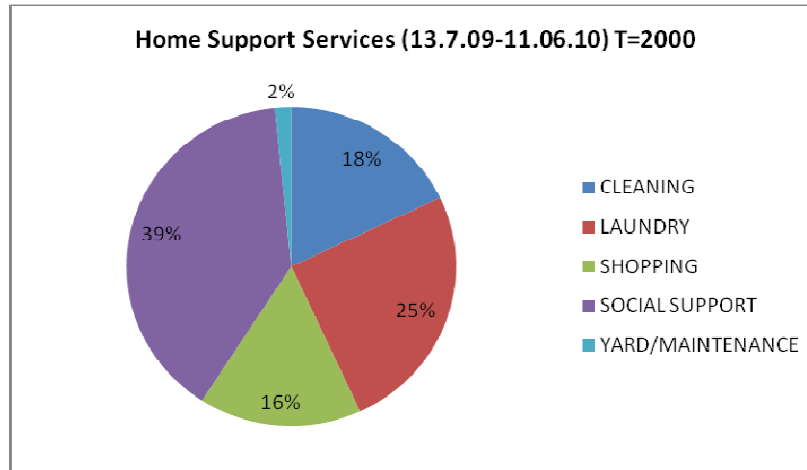
Respite/Activities

Clients have participated in culturally appropriate respite and activities. This has included fishing, art, trips to Broome as well as visiting loved ones in residential facilities. While individual activities fluctuate, overall they have increased gradually from baseline of 3 to 231 at six months and 940 at twelve months. The total number of activities participated in by carers and clients from 13.7.09- 11.06.10 was 4057.

Above: Culturally appropriate activities. Photos: McGaffin

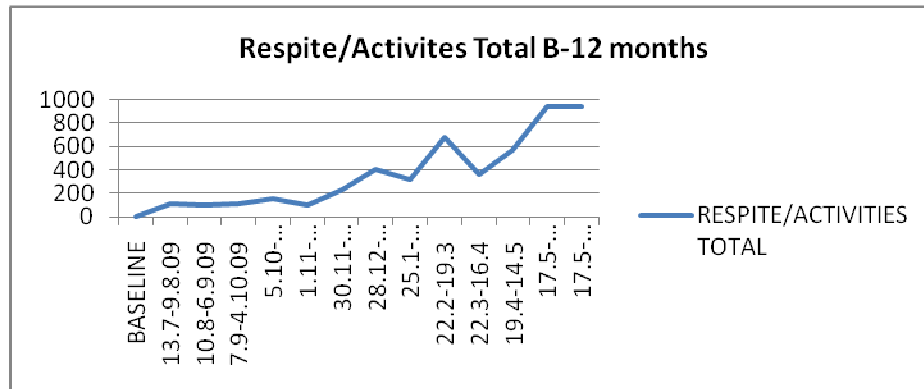Figure 7: Respite/Activities Total (Baseline to 12 Months)

Table 5: Respite/Activities Total (Baseline to 12 Months)

	BASELINE	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10
RESPITE/ACTIVITIES TOTAL	3	106	96	110	149	101	231	400	317	676	359	572	940
RESPITE CARE: DAY CENTRE OUTINGS	3	16	6	16	3	30	76	70	102	108	114	100	157
RESPITE CARE: CAMPING	0	6	0	1	3	0	0	0	0	0	0	0	0
RESPITE CARE: FISHING	0	20	15	0	11	5	4	32	2	109	56	96	280
RESPITE CARE: ART	0	16	0	0	2	0	8	167	41	23	15	55	17
RESPITE CARE: GENERAL ACTIVITIES	0	32	54	92	96	26	86	85	81	88	51	80	50
RESPITE CARE: OVERNIGHT TRIP	0	5	0	0	0	0	0	0	0	0	0	1	0
RESPITE CARE: FOR CARER	0	0	1	0	0	0	0	1	0	0	0	1	0
RESPITE CARE: BBQ/PICNIC	0	0	0	0	25	40	25	0	84	116	35	95	233
RESPITE CARE: TOWN TRIP	0	11	9	0	4	0	30	24	7	200	88	144	216
RESPITE CARE: HUNTING	0	0	11	1	5	0	2	21	0	32	0	0	0

Meals

Meals delivered to clients mainly consisted of lunch and dinner, with some breakfasts on occasion. With overcrowding, the high cost of food and poor socio-economic status combined with poor health the availability of good nutrition was seen as a high priority by caregivers in the unmet needs study. "*They need to be fed proper food…to have enough...whatever they got at*

home what's left over somebody else come to their house and say who for this food...and they can't remember sometime if they've had a meal (Carer 9)"

With support from the local nurse (who is a nutritionist), desserts are offered once a week on Wednesdays. Meals have increased in both regularity and distribution from baseline of 105 to 942 at six months and at 654 at 12 months. The total number of meals from 13.7.09-11.6.10 was 8230.

When activities such as fishing and hunting took place the resulting bush food was shared amongst clients and when possible their caregivers and families.

Figure 8: Meals Total (Baseline to 12 Months)
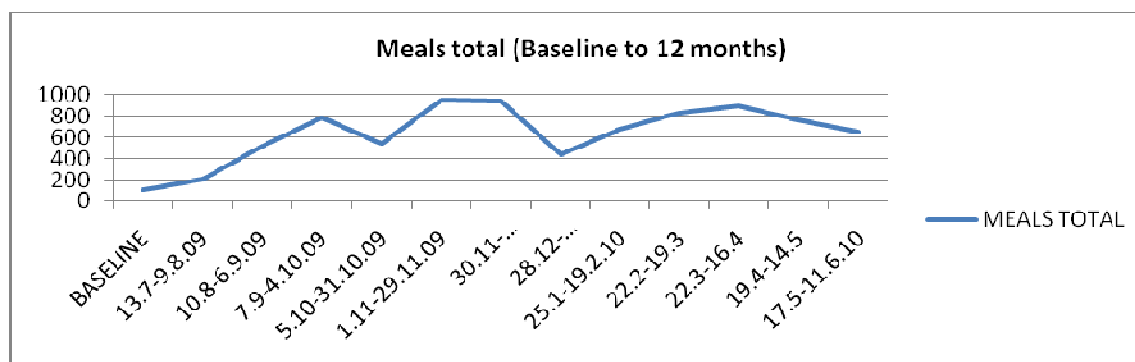
Table 6: Meals Total (Baseline to 12 Months)

	MEALS TOTAL 13.7.09-11.6.10	BASELINE	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10
MEALS TOTAL	8230	105	210	519	789	545	952	942	436	675	836	903	769	654
NUMBER OF CLIENTS ACCESSING SERVICES		11	21	23	24	25	29	29	29	29	30	30	24	22

Health assistance

Health assistance refers to assistance with medical care at home. Health assistance increased from 0 at baseline and six months to 39 at twelve months. A total of 103 health assistance services were offered between 13.7.09-11.6.10.

Figure 9: Health Assistance (Baseline to 12 months)
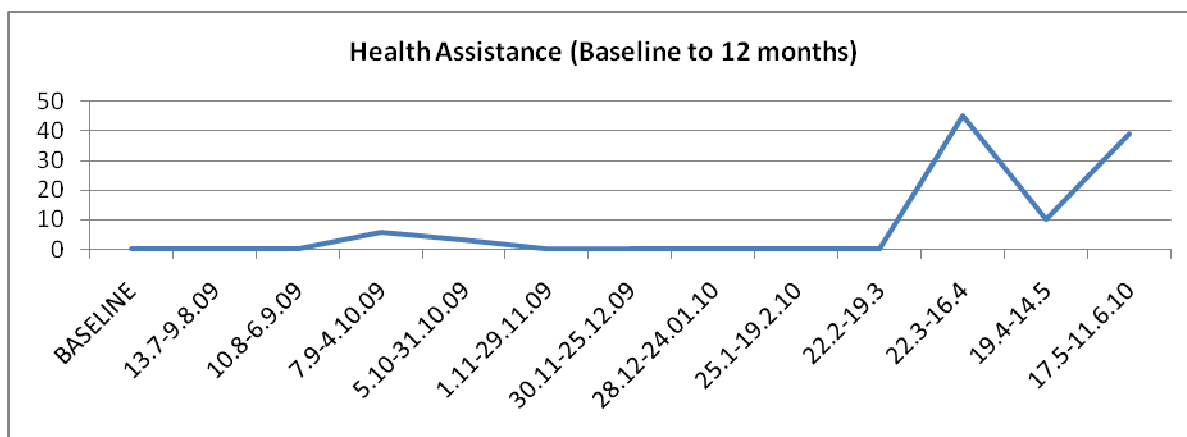

Table7: Health Assistance (Baseline to 12 Months)

	BASELINE	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10
HEALTH ASSISTANCE	0	0	0	6	3	0	0	0	0	0	45	10	39

Transport

Access to transport is an important issue in remote communities as identified in the literature review and by caregivers and service providers in the unmet needs study. "*A lot of people don't have transport. Their own transport*" (Carer 14). Transport has included (but not limited to), transport to and from appointments in town, to the clinic, to events or visiting family members in residential care. The project had originally intended to purchase a four wheel drive vehicle with wheel chair access, but was not able to secure such a vehicle within the project budget. A second hand vehicle with wheelchair access was purchased as this was the most suitable vehicle

available. A "HACC" bus was also used by the service. The need for staff members with driver's licences, and access to appropriate vehicles continues to be an issue.

Transport usage has been constant, with a sharp rise throughout the six month period from a baseline of 11 to 201 at six months and 154 at twelve months. The total transport services used from 13.7.09-11.6.10 was 1436. A spike in August (10.8-6.9) occurred, with more drivers being available for clients.

Figure 10: Transport Total (Baseline to 12 months)
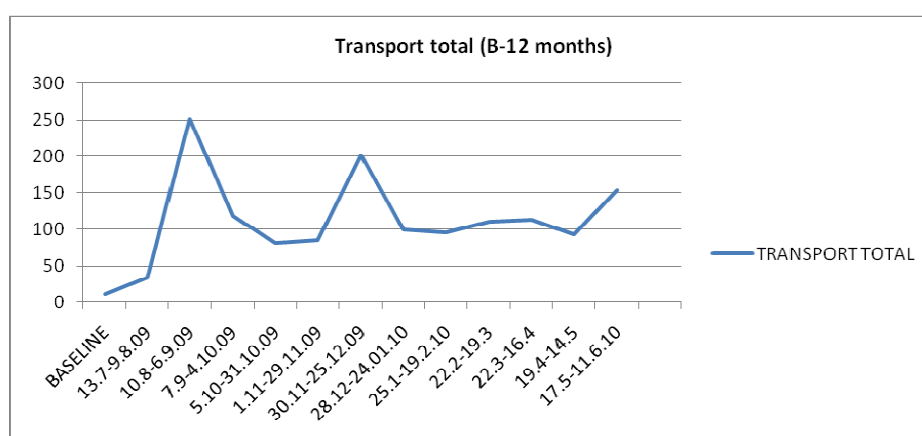
Table 8: Transport Total (Baseline to 12 months)

	BASELINE	TOTAL 13.7.09-11.6.10	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10
TRANSPORT TOTAL	11	1436	33	252	118	81	85	201	100	96	110	113	93	154

Advocacy

Advocacy refers to following up on services, direction to services, representation or other elements. Advocacy was previously identified as a key unmet need by caregivers and service

providers as stated in section two: "*There is also difficulty in communication between service providers and family carers. Service providers have a lack of awareness of what the family carers needs are*" (Service provider 3). A steady rise of total advocacy services has occurred from baseline of 0 to 115 at six months and at 131 twelve months. A total of 1303 advocacy services were offered over the twelve month period.

Figure 11: Advocacy (Baseline to 12 months)

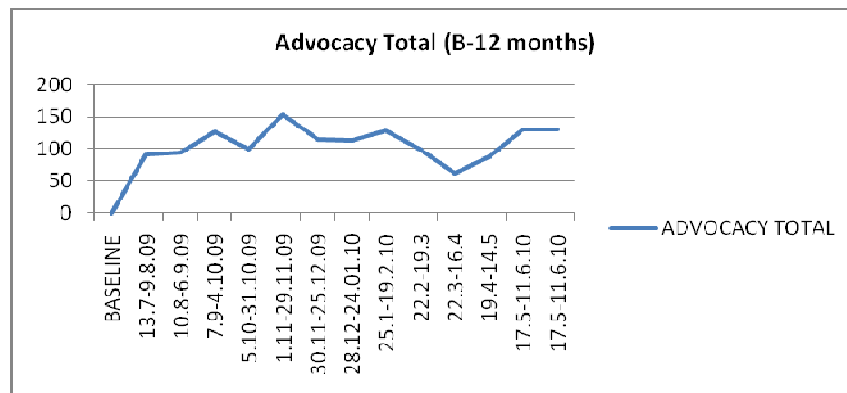

Table 9: Advocacy (Baseline to 12 months)

	BASELINE	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10
ADVOCACY TOTAL	0	92	95	126	100	154	115	113	129	99	62	87	131
ADVOCACY: FOLLOW UP ON SERVICES	0	37	46	41	48	50	19	23	6	2	3	5	5
ADVOCACY: DIRECTION TO SERVICES	0	20	0	2	1	4	4	6	29	18	3	1	3
ADVOCACY: REPRESENTATION	0	3	1	2	0	0	3	2	30	0	3	0	5
ADVOCACY: OTHER	0	32	52	103	51	100	89	82	64	79	53	81	118

Community education

Education services occurred when staff members delivered education to clients, caregivers and the community. This has included (but is not limited to) mental health, disability and aged care. Community education has taken several formats, including presentations (including to the school and football team), training workshops, posters and pamphlets.

The local action group meetings have allowed community staff to identify what resources are needed in the community, and these resources have been quickly sourced from the town-based service providers in the Local Action Group. As stated by a caregiver in section II educational resources about services were often previously kept in the town offices of service providers rather than shared with the community *"Well there should be more information given out to the families and that because not too many people know that there is help available they just government mob just keep it all within the office. I don't know who they get as field staff and that to take the information out to um educate the people on just awareness of what support is there available for people"* (Carer 14). A pamphlet on the Lungurra Ngoora Service was developed by project staff in November 2009 and is regularly handed to their community members and service providers.

Education services have risen from a baseline 0 to 95 at six months and 254 at twelve months. Total education from 13.7.09-11.6.10 was 1131.

Figure 12: Education Total (Baseline to 12 months)
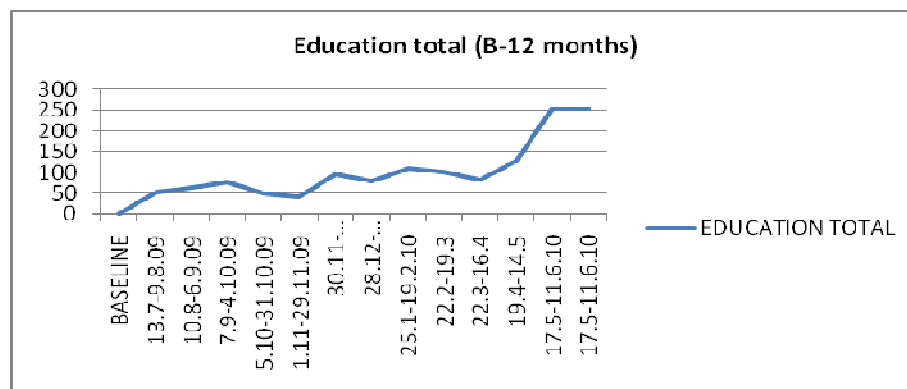
Table 10: Education Total (Baseline to 12 months)

	BASELINE	13.7-9.8.09	10.8-6.9.09	7.9-4.10.09	5.10-31.10.09	1.11-29.11.09	30.11-25.12.09	28.12-24.01.10	25.1-19.2.10	22.2-19.3	22.3-16.4	19.4-14.5	17.5-11.6.10	17.5-11.6.10
EDUCATION TOTAL	0	52	64	77	48	42	95	80	108	102	82	127	254	254
EDUCATION: AGED	0	3	0	0	1	0	5	0	4	3	4	6	12	12
EDUCATION:DISABLED	0	3	0	4	1	0	4	0	4	3	3	9	11	11
EDUCATION: MENTAL HEALTH	0	2	20	1	0	14	3	1	69	31	32	58	105	105
EDUCATION: OTHER	0	44	0	30	46	0	83	74	25	64	15	16	5	5
EDUCATION: COMMUNITY	0	0	44	42	0	28	0	5	6	1	28	38	121	121

Workforce

A key objective of the model is to increase the number of community-based Aboriginal staff who are in paid positions. This objective was identified in section II by service providers and caregivers *"There needs to be more staff in the community itself... Noted programs set up, too many white faces" (Service provider 39).*

At twelve months, six people in total are employed at Lungurra Ngoora Services and based in the community. Three positions (2 FTE) were funded through joint project funds, one (1FTE) by the HACC conversion package, and two (1.5FTE) by Job Creations packages. The council also organised two community CDEP workers to assist intermittently when needed. This had remained consistent since the six month period. The Aboriginal project coordinator had been employed full time on the project from July 2009. At 12 months of the eight staff, six individuals were Aboriginal and two were non Aboriginal. All workers until October 2009 were Aboriginal. There are an equal number of male and female workers. The community-based project coordinator provides day-to-day mentorship and support to the staff. The independent facilitator manages and supports the project coordinator with support from the community council.

Above: Clients are able to elect their preference for male or female workers.

Training and development

As stated in section II a previous gap in support for staff and the community was training: *"Distances of remote clients, don't have adequate support for either worker or client. Because of the distances education with dementia for staff and family is important"* (Service provider 16).

Steering committee, Local action group members and project staff identified training opportunities for staff members. The Lungurra Ngoora staff have attended and completed eleven

training workshops over the twelve month period. This has included Certificate III and IV in Aged Care, Mental Health First Aid, Dehydration Workshop, Alcohol and Drugs Workshop, Dementia Training, KACS Assessment training, Mental Health General Workshop and Management training. Women from Bayulu community also provided training to project staff on how they gained funding from Lotteries West for a vehicle for their community. Project staff members were also supported to gain their driver's licence, as the provision of transport was reliant on the availability of staff with licences. The community council has organised for interested Local action group members to partake in cultural training with the local school.

Above: Staff training sessions.

A council member and the project co-ordinator were funded by UWA to attend the Aged Care conference in Canberra, and while in Canberra they presented on the model to Department of Health and Ageing and Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) officials.

Above: Hon. Fred Chaney and Michelle Skinner present in Canberra

Table 11: Training Received by Lungurra Ngoora Staff

TRAINING COURSE	DATE	NO. STAFF ATTENDED
Certificate III Aged Care (Part One)- Directions Australia	22.9.09	5
Certificate III Aged Care (Part Two)- Directions Australia	26.10.09	3
Certificate IV Aged Care (Part One) – Directions Australia	22.9.09	1
Certificate IV Aged Care (Part One) – Directions Australia	26.10.09	1
Dementia Training	9.1.09	4
Dehydration Training	12.11.09	4
Mental Health First Aid (Part One)	24.11.09	2
Mental Health First Aid (Part Two)	25.11.09	2
Canberra Aged Care Conference and Training	23.11-1.12.09	1
KACS Assessment Training	2.12-3.12.09	2
Drugs and Alcohol Workshop	3.12.09	2
Mental health workshop	3.5.2010	2
Management training	June 2010	1

Community consultation

Looma Council participated in all decision making processes regarding the project. As stated by a community-based worker in section II: "*Countrymen could also assist the agencies coming in by identifying what services they want in their community and how to implement those programs*" (Community worker 10)

Two Council members attended all steering committee meetings and reported back to the Looma Council. Elders of the community were regularly consulted regarding the project. In addition, Looma Council regularly gave advice and feedback to the project staff and research team. This process allowed the Council to be aware of the progress of the project and actively control any decisions. Looma Council also offered their boardroom for group activities and meetings for the services. These included art, morning tea, group feedback from clients to Lungurra Ngoora and other activities. In addition to community feedback and participation, the local elders

collaborated to name the service in September 2009, "Lungurra Ngoora Services" - Blue Tongue Lizard Home in Walmajarri language (see picture below). The name relates to the dreaming for the Looma Community. The group chose to use the blue tongue lizard as the logo for the project.

Service co ordination and communication

A key objective of the project was to improve service coordination and communication. This included between services, between services and the remote community and between the services and local community. As a caregiver stated in section two: "*They should be working in closer like err well it should be a two way thing community and the service provider and the carer and the person that's being cared for and the whole family in general that sort of thing gotta be sit down and worked out together*" (Carer 41).

The steering committee, comprising of the key agencies developed shared strategies and plans for the project. Steering committee meetings were held on a bi-monthly basis from March 2009 to June 2010. Members attended in person or via teleconferencing. On the occasions members were not able to attend, they received minutes and feedback from the meeting. Looma Council members were present at every steering committee meeting and provided community feedback at each meeting, with time put aside during each meeting for the community report. Interagency representation at fortnightly local action group meetings assisted with client care planning, communication and sharing of knowledge. Due to on-the-ground staff and regular meetings, clients stopped falling through the system. The benefits of service coordination through formal

fortnightly to monthly local action group meetings were identified in the testimonials from local action group members, see Appendix III-V.

In addition to the local action group, updates regarding the service were featured in the local Derby newspaper, "The Muddy Waters", as well as the Indigenous Study Newsletter to keep the surrounding communities aware of Lungurra Ngoora services.

An additional benefit of having a community-based service, with a non-government organization as the facilitator has been the valued support from businesses. Local businesses have showed their support by donating products to the community service. These businesses included The Boab Pharmacy, Home Hardware, BK Concreting & Earthworks Pty Ltd, Mitre 10,Woolworths Derby & Broome, Mantra Hotel, Camballin Corner Shop, Sound Plus, Toy World Derby, Rusty's IGA Derby, Totally Work Wear Derby and Troppo Pets.

Accountability

Through formal collaboration services have been more accountable to Looma clients and caregivers, the community and to each other. As stated in section II collaboration of services and the community can lead to better client care:*"For people to stay for longer in community there needs to be better liaison, which would result in a smoother ride for the client and more of an understanding"* (Service provider 16).

Service accountability has been reflected in a number of ways. The local action group meetings provide a formal method to ensure service providers honour their commitments to the community. There has been greater numbers of following up on services by the project coordinator (see "Advocacy: Follow up on Services). The project coordinator position has been crucial in advocacy such as following up with services, updating information for agencies and on the ground logistics. The coordinator and service agencies discuss case management in local action group meetings, allowing for shorter referral intervals and follow-up on outcomes. The community-based staff members were great advocates for the clients, leading to greater engagement by services with the clients and their families.

Service agencies are now signing the service and community visitor book, which improves community governance (see Appendix VIII). Steering committee members ensured that government standards for their service were being met. The Lungurra Ngoora Feedback/Service Improvement Survey enables clients and caregivers of the service to provide feedback and suggest ways to improve the service (see Appendix I).

Kimberley Aged and Community Services held the project budget, and provided a financial manager at no cost. Having a separate fund holder to facilitator is contrary to the model and has not been ideal, resulting in more complicated administrative processes. It is recommended that they are administered by the same organisation in the future. The KACS manager presented a financial report to the steering committee at every bi-monthly meeting, outlining that the project was either on or below budget at the time of each report. Due to outstanding invoices the 12 month financial report will not be completed by KACS and made available to the steering committee members and funding bodies until 30th September 2010.

Discussion

The project, developed from extensive qualitative research, has lead to effective and equitable service delivery to the frail aged, people of all aged with disabilities and mental illness, and their caregivers living in Looma community. There have been dramatic improvements in service delivery from before the trial began, when as stated in the unmet needs study in section II *"There is nothing to refer old people to in remote communities. Remote HACC is often not working"* (Service provider 21). "*04 explained that in Looma, which was struggling a little with aged care service provision, that for a long time the older people who chuck in $5 a day for their meals were only been fed frankfurts as this is cheap and easy"* (Service provider 4). The dramatic improvements detailed in section III have occurred for the benefit of people of all ages with disabling conditions and their caregivers through a collaborative approach, with the specialised government services and non-government organisations working together in formal partnership with the community, enabling the community members to have a sense of control over their service, without services abdicating their responsibilities.

The project has been embraced by Looma Community for many reasons. Strengthening capacity of the community through genuine consultation, real employment opportunities, on the ground management of staff, and ongoing training and development are direct tangible benefits. Clients and families in need (including those previously falling through the gaps) were identified, they were provided with one access point in the community to services, they received greater access

to a breadth of services not previously available in the community and were able to feedback their ideas on how to improve the service. The contribution of the community council, clients and caregivers enabled the community to develop a sense of control over their service. There are also many benefits to the service providers themselves. Formal partnerships resulting in greater collaboration and coordination between services, and services and the community, may strengthen service efficiency and quality, and improve the long term health and well being of their target group.

The following shared objectives were developed with all of the representatives of the Lungurra Ngoora Steering committee. All of the objectives have been met by the project and are summarised briefly below:

Table 12: Steering Committee objectives and examples of how they have been met

Key objective: **To optimize the health and well-being of the frail aged and people of all ages with disabilities and mental illness living in Looma community and their caregivers.**

Further objectives: **The project will:**

1. **Identify the frail aged and people who have disabilities (cognitive, intellectual, sensory, psychological and physical) living in Looma community and their caregivers. This has been met through collaborative partnerships with key service providers and community-based staff identifying eligible and interested clients. Clients range across the aged, mental health and disability needs and the number of clients has increased from 8 to 22.**

2. **Identify the needs of the frail aged and people with disabilities or mental illness and their caregivers in Looma community. Community workers, the project co coordinator and service partners have worked closely together to identify and meet the needs of clients and their families. This has been demonstrated in client feedback forms, number of clients and caregiver wanting to access the service and a broader range of services available.**

3. **Increase service use for this target group. Service usage has increased from 140 per month at baseline (18 per client) to 2395 per month at twelve months (109 per client). This has been a consistent increase in range of services, usage of all services and number of clients using services.**

4. **Employ a holistic, inclusive and creative approach to meet client and caregiver needs. In partnership with the community, client, carer, on the ground staff and service providers, the depth and range of**

5. **Develop a blueprint of the model that is transferrable to other Aboriginal communities.** In addition to this report further details on model development and the project resources can be accessed from Dina.Logiudice@mh.org.au

Dementia guidelines

Best practice guidelines for dementia care in the Kimberley were developed with assistance from project partners Kimberley Aboriginal Medical Services Council (KAMSC) and can be accessed on the website www.kamsc.org.au/resources/resourceguidelines.html

Meeting the challenges in remote communities

Due to the nature of the model the service was flexible enough to withstand and grow when faced with the challenges that are often faced in remote communities.

The changes to CDEP in 2009 resulted in the loss of funding for the CEO for some months. The independence of the service from previous reliance on the CEO position, the genuine involvement of the Looma Council and the coordinator being based in the community has prevented these changes from affecting the continuation of the project.

When staff resigned the Looma Council immediately provided advice and direction in employing new community members. The Council directly identified possible individuals in the community who might be suitable for the vacant positions, which has been one of many valuable contributions. The presence of the coordinator in the community also enabled positions to be filled quickly, usually within 24 hours. The project co-ordinator mentored and supported staff and was supported by facilitator and Council. Work readiness skills were taught and quickly adopted as regular feedback was available, such as applying for leave in advance.

A challenge with transport has been a shortage of staff with driver's licenses. The project assists staff with the costs for obtaining their license. This is an area which can be further developed by continuing to up skill a pool of casual drivers.

Previous challenges faced by key service providers being based in town were overcome by having community-based staff, who delivered services to meet their clients and caregivers. The community-based staff members were great advocates for the clients, leading to greater engagement by services with the clients and their families. The project co-ordinator acted as one access point for community members to access services and an access point for service providers to access clients in the community.

An independent facilitator ensured that the service providers actively collaborated with the community council, ensuring that the community council had an active voice on the committee and that any difference of opinion with the steering committee was discussed and resolved at these meetings.

Although not recommended in the proposed model, due to initial difficulties in engaging a facilitator the fund-holder and facilitator were separate organisations during the trial period. This led to more complex administrative processes than necessary. It is recommended that project funds are held by the independent facilitator in the future.

Limitations in data collection
The HACC tick sheet format changed several times so that some services may not have been captured. An additional measure (known as the research tick sheet) was used to identify other services provided over the 12 months (e.g. advocacy and education). The tick sheets did not allow for the comprehensive recording of caregiver support and this should be addressed in future evaluations. Caregiver feedback was received through the Project Feedback/Service Improvement Surveys, and the Yarmintali Consultancy external evaluation.

Key Recommendations
The following recommendations are crucial to the success and sustainability of a model of care, with the potential for expansion to other areas of the region given genuine collaboration and consultation with interested communities. These recommendations address the unmet needs identified through extensive consultation with Aboriginal communities and regional service providers and outlined in section 2, namely genuine community consultation, service coordination and communication, community based services, culturally secure services,

Aboriginal workforce with local guidance and support, and education and training. The recommendations have been summarised below.

> **Formal partnerships, cooperation and collaboration** between service providers and community. The model ensures the formal collaboration of service providers with each other and the Aboriginal community at all levels. The steering committee co-funds and co-directs the project, assisted in the collaboration process by the independent facilitator. Organisations commit to and sign a service agreement which identifies the shared objectives that they co-developed and outlines their role. The values of mutual respect, ability to be flexible and innovative, and to work within a team are key attributes for the steering committee. The guidance of the steering committee and the local action group is invaluable for the success of the project.

> **Genuine community consultation, guidance and decision making**. The community must be involved in all aspects of decision making including project design, consultation, management and feedback. Decreasing reliance on transient positions (such as the community CEO) through formal community council engagement at the strategic management level prevents regular changes in the administration staff from halting the delivery of services. The regular survey of community clients and caregivers on ways to improve the service is recommended.

> An **independent facilitator** to ensure collaboration and assist with direction of common goals. If possible the role should be filled by a non-government organisation to assist in facilitating the variety of specialised service providers and industry to work together with the community and pool resources to provide one on-the-ground service, to mediate interests, to ensure a focus on community development and to engage local businesses. It is recommended that the facilitator holds the project funds and employs staff members to simplify administrative procedures.

> **Flexibility** of service providers, staff and the service. The service needs to be flexible and responsive to the needs of clients, caregivers, the community and the staff. It is recommended that a pool of community-based workers are employed and trained to provide a range of services (see recommended model of care, figure 13 below)

> **Culturally secure and community-based service.** Employment of preferably Aboriginal staff members who are supported in the community and guidance from the community council capitalises on local knowledge and builds community capacity. It also enables the service to meet the specific needs of each community. It is recommended that the project coordinator

works with the community council to identify and recommend potential workers from the community. This also enables positions to be filled quickly.

➢ **Community based support, mentorship, training and development of staff.** It is recommended that steering committee and local action group members are actively encouraged at each meeting to identify new training opportunities and resources available to the community members and project staff and assist in accessing these. The community-based project coordinator provides day to day mentorship and support to the staff. The independent facilitator manages and supports the project coordinator with support from the community council. As transport is a key issue for clients and caregivers, all project staff should be supported to gain their driver's licence where possible.

➢ Ongoing **advocacy** for clients and families. The project coordinator provides one access point in the community for clients, caregivers, the council and service providers. This has assisted in the smooth delivery of services. Outstanding service delivery issues for clients and caregivers (such as installation of equipment, need for an interpreter or health care issues) can be efficiently followed-up by the project coordinator, or jointly coordinated at local action group meetings.

Figure 14: Recommended model of care
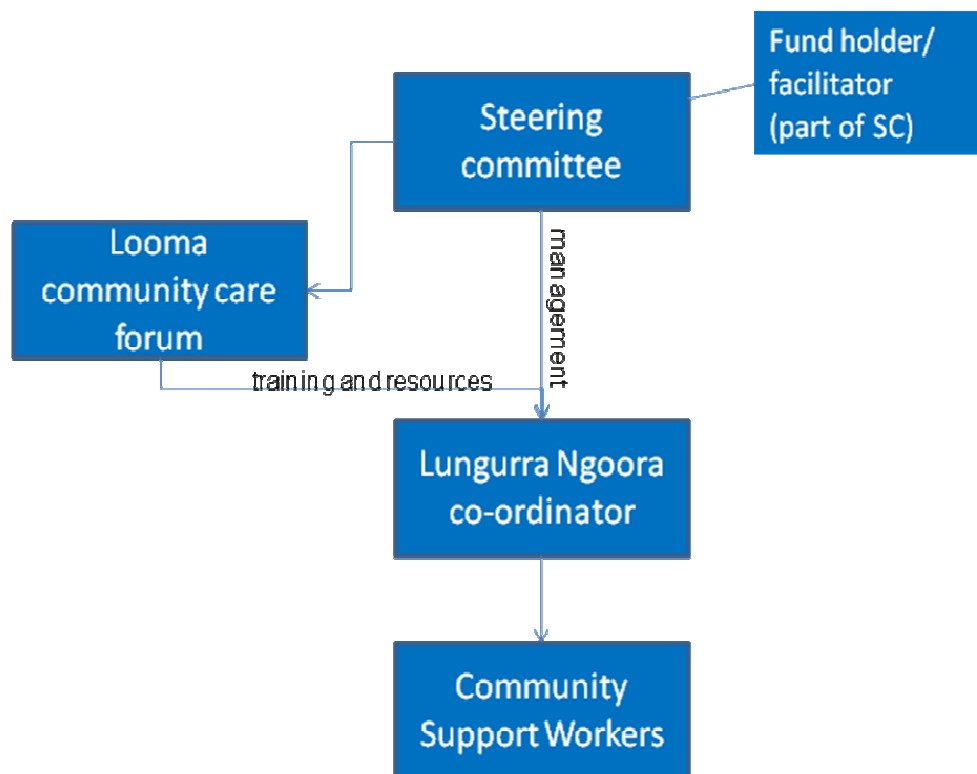
Future of the Lungurra Ngoora Service

A meeting was held in May 2010 to discuss the future of the project with funding bodies (HACC, Mental health and DSC) and steering committee members. At this meeting the Looma Council representatives stated their wish for the project to continue and their preference for the non-government organisation currently in the role to continue as facilitator and to hold the project funds. The Council representatives also asked for project staff to be employed through the non government organisation rather than the council due to regular periods without a community accountant and CEO, leading to difficulties in managing staff salaries, and for the current project coordinator to remain on in their role. Continued funding by the three main funding bodies was agreed to at the meeting. The expansion of this service model to other interested remote communities in the region was discussed as a future possibility.

In the interim the key funding body, Home and Community Care (HACC), announced their decision to appoint the regional government aged care service as facilitator and fund-holder for the project over a one year period, to be evaluated in their role by an external evaluator over this time. As funding is not immediately available to continue the current model service, HACC are seeking growth funding to continue the delivery of services in Looma community following some of the model components. As such Lungurra Ngoora staff contracts have not at this stage been renewed. The Looma Council and community are hoping for the recommencement of the program soon on a more permanent basis.

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Appendices

Appendix I: Client and caregiver service improvement form

Lungurra Ngoora Service
Feedback/Service improvement survey

In order to keep improving the quality of our service we would appreciate it if you could help us fill out the following survey.

Name : _____

1. Are you happy with the quality of the Service you receive?

   Yes ☑   No ☐

   Comments:

2. What do you like about the Service?

   Comments:

   This Service is Running real good.
   I have No problem

3. Has having Lungurra Ngoora Community Service working in the community made a difference to your health and how you feel?

   Yes it does and Im happy for it

4. How can the service be improved?

   I like To See TRANSPORTa.
   happening taking for nde.
   And other then that the Service is
   real good

Appendix II: Letter from community council

05/08/2009

To Aged & Disability Service & Looma HACC,

The community and council would like to say congratulations and what a great job you are doing for the Looma community. We have noticed a difference in the past three weeks with the introduction of the three meals and the service that is offered for the people in the community. Everyone is talking about it. Some people are still talking about their trips they have had.

Keep up the great work

HARRY   CHAIRPERSON
SKINNER

(signature) Council

Appendix III: Letter from Derby Allied Health (Local action group member)

Government of **Western Australia**
Department of **Health**
WA Country Health Service

DERBY HEALTH SERVICES
Occupational Therapy Department
Clarendon Street (PMB 938)
Derby WA 6728
Tel: **(08) 9193 3219**
Fax: **(08) 9193 3376**

3rd **August 2010**

TO WHOM IT MAY CONCERN

I am writing this letter on behalf of the Allied Health team from WA Country Health Service – West Kimberley, to express support for the Lungurra Ngoora Community Care Service Project in Looma community.

Our Allied Health team provides outreach Physiotherapy, Occupational Therapy and Speech Pathology services to communities in the West Kimberley, including visiting Looma every 4-6 weeks. We provide multidisciplinary services to children and adults in the community, including those with disabilities and age-related reduced function and mobility.

Prior to the commencement of the Lungurra Ngoora Community Care Service Project, we would often experience difficulties with efficiency and service provision due to reduced communication and reduced support for our clients in between Allied Health visits. For example, often we would not be aware that a client required a particular piece of equipment prior to our arriving, resulting in delayed time for the client to receive the equipment as they would have to wait until we returned to Derby, got the equipment sent out, and then could install and provide education on the following visit. This resulted in delays in service provision for the clients, decreased their level of safety, and caused cost inefficiencies in our service.

Since the program commenced, our services have been markedly more efficient, resulting in improved service and care for our clients. The project coordinator in Looma would contact us prior to our coming, and let us know of particular client needs prior to our visiting. We received earlier, more appropriate referrals for clients, and were able to assess and treat clients more efficiently and effectively. We were able to utilise

Lungurra Ngoora Community Care Service Project employees to provide basic rehabilitation services in our absence, resulting in improved client outcomes and reducing the likelihood of representation to hospital.

One particular client in Looma has a severe condition which limits his ability to walk or manage his personal hygiene independently. Prior to the Lungurra Ngoora Community Care Service Project, this gentleman was in bed in a poor state of hygiene every time Allied Health visited him at home in Looma. He had not walked for many months, and was unable to access his toilet or shower. His mental state was very low. However, the project has enabled this gentleman to receive personal care services, thus improving his personal hygiene, and have enabled him to partake in valued activities such as fishing down at the river. When we last visited Looma he was sitting on the veranda, in a cheerful state, and keen to show us how he could now take a few steps. The improvement in his wellbeing over the past 12 months has been remarkable, and I have no doubt that this gentleman would not have such significantly improved well-being if it were not for the services of the Lungurra Ngoora Community Care Service Project which have allowed him to re-engage with his community.

I fully support the continuation of the Lungurra Ngoora Community Care Service Project due to the positive outcomes for the people of Looma, as well as the improved efficiency of our Allied Health services to the community.

Please contact me if you would like to discuss further

Kind regards

Robyn Doney

Occupational Therapist
Derby & Fitzroy Valley Health Services
PMB 938, DERBY WA 6728
Phone: 9193 3219
Fax: 9193 3376

Appendix IV: Letter from DSC Area Coordinator (Local Action Group)

5 May 2010

Local Area Coordination

Dear Sir/Madam

REF: TO WHOM IT MAY CONCERN

I am writing to support the Lungurra Ngoora Community Care Service Project (LNCCS) at Looma and the significant value it provides to people who have a disability and their families.

Prior to the service commencing in 2009, I visited Looma several times a year in my role as the Local Area Coordinator. Whilst I could visit the DSC eligible people and provide much needed advocacy, the frequency of contact was impacted by the distance between Looma and Derby. Therefore this situation presented many challenges in establishing and maintaining good solid, local support options.

The LNCCS now provides the first point of contact to these people and I am aware that the program has been successful in providing valuable support. Feedback from participants is very positive and suggests that their quality of life, participation and contribution in their local community has been enhanced. People appreciate having access to a local service provider who can respond to their immediate needs in a practical way ie, community engagement, facilitating meetings. One man is now working part time in the community store as a result of this service while others report taking advantage of respite opportunities etc. Another notable achievement of the service is its capacity to bring agencies together to work in collaboration around the individuals and the community.

Regards,

Milton
LAC - Derby
Disability Services Commission
Office Hours: Monday to Wednesday 8:00am to 4:30pm
t: (08) 9191 2411
f: (08) 9191 2411
e: Milton.Mupotaringa@dsc.wa.gov.au

Appendix V: Letter from Mental Health Worker (Local Action Group)

WA Country Health Service
Government of Western Australia

Kimberley

KIMBERLEY MENTAL HEALTH AND DRUG SERVICE
Derby Office
Cnr Neville & Claredon Streets Derby Western Australia 6728
Tel: (08) 9193 1633   Fax: Clinic (08) 9193 1687
ABN 28680145816

12 May 2010

To whom it may concern

Letter of support for the Looma Lungarra Ngorra Community Care Service Project

I am writing this letter in support of the Lungarra Ngorra Community Care Service Project based at Looma Community.

This project has been beneficial to Kimberley Mental Health and Drug Service (KMHDS) clients and to KMHDS as a service provider in terms of providing extra information and monitoring of our clients at the Looma remote community. KMHDS conducts fortnightly outreach visits to Looma, and the extra information and interaction with our clients is of great benefit to them.

Looma Project staff helps monitor our clients' medication adherence, and encourage and assist them in social interactions and in their in daily activities, as required. This assistance and facilitation of social interactions and community involvement provides a greater quality of life to our clients, and to Looma Community as a whole.

The Looma Project also assists clients in accessing appropriate services within Derby.

Since the inception of the Looma Project, I have seen great improvements within our clients. Whom receiving long term treatment, counseling and social support.

Looma Project participants have given positive feedback to KMHDS on the clients we share, and are always willing to listen to KMHDS input and provide information relevant to client care.

If you have any queries please contact me on (08) 9193 16 33 .

Yours sincerely

Estelle Injie
Mental Health Worker
Kimberley Mental Health & Drug Services
Corner Neville & Clarendon St, Derby WA
Phone: (08) 9193 1633
Fax: (08) 9193 1687
Estelle.Ingie@health.wa.gov.au

Appendix VI: HACC tick sheet example

Looma Community   HACC   week beginning 30.11./2009 to 6.12./2009

(period 30.11.09 → 25.12.09).

Appendix VII: Research tick sheet example

LOOMA LUNGURRA NGOORA PROJECT: WEEKLY RESEARCH STATISTICS SHEET

NAME (client/carer) or Community Group	RESPITE/ACTIVITIES							ADVOCACY				EDUCATION					MED	
	C	F	A	B	T	H	Oth	FU	D	R	Oth	Ag	Di	MH	C	Oth	Mo	Oth
							✓	✓	✓	✓	✓					✓		
		✓					✓	✓	✓		✓					✓		
		✓					✓	✓	✓	✓	✓					✓		
		✓			✓		✓	✓			✓					✓		
							✓	✓			✓					✓		
							✓	✓			✓					✓		
							✓	✓			✓					✓		
						✓	✓	✓			✓					✓		
			✓				✓	✓			✓					✓		
			✓	✓			✓	✓			✓					✓		
							✓	✓			✓					✓		
			✓				✓	✓			✓					✓		
		✓	✓	✓			✓	✓			✓					✓		
		✓	✓				✓	✓			✓					✓		
(carer)					✓		✓	✓	✓	✓	✓	✓	✓			✓		
		✓	✓		✓		✓				✓							

Appendix VIII: Example of Visitor's book

Date	Name	Address		
2009				
2/10		Alchin – KACS		
23/10		Mental Health · Management		
23/10		SMYL		
26/10		Moruya, NSW,	Directions Austral.	
1/11/09		KMHDS Derby		
/11/09		KMHRS Derby		
/11/09		Derby		
/11/09		Alchin KACS		
4/11/09		KMHDS – Derby		
11/11/09		Derbal Brogan Hostel. Playhouse		
		WA 6081		
/11/09		Derby Health Service		
/11/09		BROOME – KACS		
2/11/09	A	KACS-Derby		
5/11/09		KMHDS	Clients.	
6·11·09		KMHDS	CLIENTS	
6/11/09		DSC	CLIENTS	
6/11/09		Derby Hospital		
/11/09		Derby		
9/11·09		KMHDS	Clients	
2/12/09		DSC		
12/12/09		KACS.		
12/12/09		KACS		
22/12/09		KACS		
23/12/09		Alchin KACS –		
4/12/09		Frontier Services.		
4/12/09		Frontier Services		