

A.O.C. 10/7/08

Submission No. 685

(Inq into better support for carers)



Carers NT Inc

**Submission to the House of Representatives Family and
Community Committee on the Future Needs and Support for
family carers.**

July 2008

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1. Executive Summary & Recommendations

Carers NT is the peak organisation representing the Northern Territory's 30,000 unpaid family carers, who are providing care for people with disabilities, mental or chronic illness or are aged and frail.

This submission concentrates upon two specific issues. Firstly, those which effect Indigenous carers on isolated communities in the Top End of the Northern Territory. Secondly the need for scientifically based research to support quality interventions with carers. The wider areas of concern to carers are addressed in submissions to the Committee from Carers Australia and various State and Territory Carer Associations. We fully endorse these submissions.

Indigenous people living in remote communities in the Northern Territory experience similar problems associated with their provision of care as do carers in the wider Australia community. The lenses of poverty, geography, culture, language, and lack of services magnify these. Together these issues combine to make the provision of adequate care to a family member or friend who is frail aged, chronically ill, or who lives with a disability extremely difficult. Yet it is the lot of many people living in these communities, and a task that is undertaken with love and dedication.

This submission makes use of the stories of a number of carers and care recipients. In most cases real names have been used, in a few cases names have been changed to protect privacy when this has been requested. The stories are used to illustrate issues faced by these carers, and to cast light on wider issues associated with caring. These are real people in real situations their stories are current.

In our experience most carers will continue to provide care for their relatives and friends despite what most of us would consider overwhelming odds. It is a mark of the nature of a community as to how these carers are supported. Australia leads the World in carer support in many ways, however much more needs to be done before carers are adequately resourced and recognised. Carers NT attempts to provide quality services to the carer. However there is little research which has been undertaken as to the 'best' forms of intervention. We believe that this lack of objective

information leads to service delivery which may not be as effective as it could be. The Australian community want evidence based practice; we must support the collection of this evidence.

The following recommendations may assist the Committee in its deliberations.

Recommendation 1

Centrelink be instructed to provide proper assistance to carers to ensure that carers are able to access the Carer Payment and Carer Allowance despite the carers difficulty with language, literacy, isolation and cultural background.

Recommendation 2

Centrelink be instructed to simplify application forms for Carer Payments and Carers Allowances so that carers who are already under stress can complete these forms

Recommendation 3

Funding be provided to ensure that adequate equipment is provided to allow carers to provide care for their care recipient safely and with dignity. That this funding includes resources to repair and maintain equipment.

Recommendation 4

The cost of transport of fresh food and vegetables to isolated communities with high levels of unemployment be subsidised by the Federal Government.

Recommendation 5

Adequate housing be provided on indigenous communities and this housing is modified to allow care to be provided safely and with dignity.

Recommendation 6

Adequate trained interpreters to be made available to support carers in their dealings with medical and welfare service providers

Recommendation 7

Service delivery agencies operating on indigenous communities be provided with funding to provide adequate transport to allow the service to be delivered in a culturally appropriate manner. A vehicle to pick up recipients to go to and from the Day Centre, the Clinic and the store would be a huge bonus.

Recommendation 8

That carers providing care for multiple recipients are paid a Carers Allowance for each of the people they care for.

Recommendation 9

Each substantive community is provided with a day respite facility so that carers can have a rest. These facilities do not have to be 'flash'. A room with mattresses, water, shower, washing machine and cooking facilities will be adequate. They will need to employ a person to provide the respite care, probably a person from outside the cultural group.

Recommendation 10

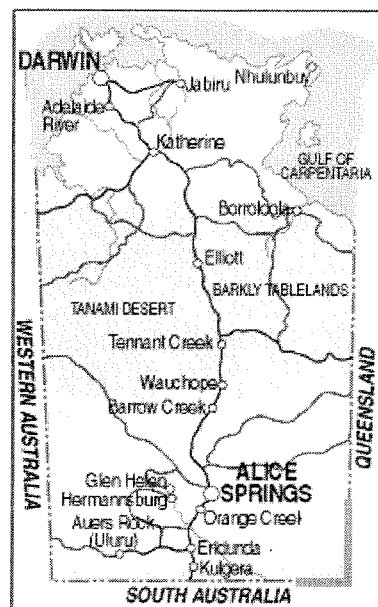
Service delivery agencies providing support to carers and care facilities are adequately funded by all Departments to ensure that appropriate services can be put in place.

Recommendation 11

The Committee recognise that research into most effective forms of service delivery to carers is part of any consideration for the future needs of carers and that adequate funding and support be provided to allow this form of research to be undertaken.

2 The Territory in Context

The population of the Northern Territory is 200,000 people of which approximately 30% (70,000) are indigenous. This population is spread over a land area of 1.35 million hectares, although 70% of this population lives in the 'urban' settings of Greater Darwin (120,000), Alice Spring (26,500), Katherine (9,000) or Tennant Creek (3,000). There are an estimated 20,000 Indigenous people living in these 'urban' settings, i.e. approximately 30% of the Indigenous population. The remainder live in small towns or 'communities', many of which are on land owned by the Aboriginals.



The issues associated with support for carers in the Northern Territory are associated with a small population spread over a huge geographical area.

3. Carers NT: Who we are and what we do.

Carers NT is the peak organisation representing the Northern Territory's estimated 30,000 unpaid family carers, who are providing care for people with disabilities, mental or chronic illness or are aged and frail. We celebrated fifteen years contribution to the Territory community in 2007.

Our vision is to have a community in which carers are recognised and valued as an important community asset in which our client group have access to adequate, timely and appropriate services that are delivered in a respectful manner.

Our mission is to enhance the quality of life for our client groups in the Northern Territory by providing:

- Quality service delivery;
- Community development, education, information and awareness;
- Advocacy;
- Involvement in public policy formulation as it relates to carers.

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Our experience is that the vast majority of family carers will continue to care, even in the face of almost insurmountable odds. What carers need is adequate support and recognition delivered with respect and dignity.

Quality Service delivery has been the focus of Carers NT for most of our history. Given the lack of alternative service providers we auspice a portfolio of services which include:

- The Northern Region Commonwealth Respite and Carelink Centre, funded primarily by DoHa, which provides respite short term and emergency respite across the Top End of the Territory. This area is approx 500,000 hectares stretching from the east to west borders of the Territory. The town of Elliot marks the southern extremity of our area of operation, it stretches to the various islands off the north coast;
- The Carer Advisory Centre, primarily funded by DoHA, which provides advocacy, education and training, counselling and support for carers with multiple issues across the Territory;
- Remote Respite Programs which provides culturally appropriate respite to carers living on isolated Indigenous communities in the Top End. This is funded by DoHA.
- Mental Health Respite programs funded by FaHCSIA;
- Volunteer program which places trained volunteers with people who are socially isolated in the Darwin Region (funded by the Territory Government through HACC:
- Music Therapy for carers and care recipients in the Darwin Region funded through CSTDA;

Carers NT- Submission to House of Representatives Family and Community Committee on the needs of Carers.

- A fledgling support worker program which employs, trains and places paid support workers with families in receipt of CACP, EACH, HACC and Respite services.

Our advocacy for carers is based on the following six principles:

- caring is a personal, social and public responsibility shared by individuals, families, business, community organisations, public institutions and all levels of government.
- carers are recognised and valued for their important contribution to the wellbeing of the Australian community and the people whom they support and for their unique expertise and skills in the caring role.
- carers are also recognised as individuals with their own needs within and beyond the caring situation.
- carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.
- carers are included in decision-making that relates to their care situation and impacts on their lives. Carers have a voice in legislation, policy and program development, service implementation and evaluation across all sectors.
- carers are able to access a wide range of information and resources, informal support and responsive, affordable services to complement caring. They are entitled to carer friendly policies and practices in other areas of their lives.

4. Limits to this submission

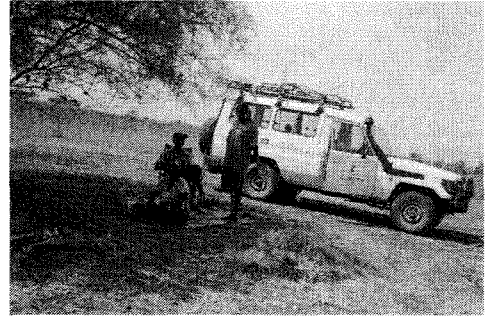
Carers NT is part of the Network of Carer Associations comprising Carers Australia and Carer Associations in each of the States and Territories. Carer Australia will be making a submission to the committee, as will other State and Territory Associations. We fully endorse these submissions, therefore we have not included too much in the way of statistical data. Rather we are telling the story as we understand it from the point of view of carers and practitioners working with carers. In this submission we focus on two issues that are dear to our heart and which may provide a slightly different perspective on carers issues. Our focus is on:

- Issues associated with indigenous carers living on remote communities across the Top End. We are sure that many of these issues will be similar to those experienced by isolated indigenous carers in the southern part of the Territory, as well as other parts of Australia, We have chosen to concentrate on issues and examples from communities with which we have experience as a service delivery agency. The people mentioned in this submission are real, their issues are current.
- The need for research into the interventions with carers that work. We have undertaken a significant literature research which clearly shows that, while the 'problems' associated with caring are significantly investigated, there is little evidence based literature on how these problems may be addressed.

5. Specific Issues facing Indigenous Carers on Top End Communities

This organisation feels confident in making a

submission focused on indigenous carers because we have consulted widely with carers and because we work with indigenous carers on a daily basis. Carers NT has provided respite services to Indigenous carers living in the Top End for a decade and a half. Initially this was primarily through the operation of Northern Region Carer



Hunting provides health food.

Respite Centre. The lack of brokerable services on most communities meant that until 2002 this service was largely limited to arranging respite for carer by removing the care recipient from a community and placing him or her in a nursing home in either Darwin or Katherine. This approach was not liked by either the carers or the care recipients. From 2002, thanks to funding provided by DoHA, we have operated a Responsive Respite service we call the 'Troopy Program'

The 'Troopy program' works on the deceptively simple approach of providing carers living on communities with the opportunity to take culturally appropriate respite without removing either the care recipient or the carer from their community. We do this by providing a remote community with a 4W drive vehicle, Toyota Land Cruiser Troop Carrier (a Troopy) for a period of 4 to 6 weeks. During this period the carers on the community utilise the vehicle and associated camping equipment to take respite. This respite includes activities such as:

- return to country;
- hunting
- gathering 'bush tucker';
- shopping; or
- attendance at funerals and ceremonies.

The program is highly successful measured by the responses of participants and the enthusiasm of health centres and other community organisations who host the program. We started with one vehicle, we now operate with five. There is a high demand for the program from the communities. We believe our model works while

others have failed because we 'trust' the communities to operate the program in a manner which is appropriate to them. Our staff members also spend a great deal of time developing real and trusting relationships with carers on these communities.

Indigenous people living in remote communities in the Northern Territory experience similar problems associated with their provision of care as do carers in the wider Australia community. The lenses of geography, culture, language and lack of services magnify these. Together these issues combine to make the provision of adequate care to a family member or friend who is frail aged, chronically ill, or who lives with a disability extremely difficult. Yet it is the lot of many people living in these communities, and a task that is undertaken with love and dedication.

This submission highlights nine matters which impact upon carers on isolated communities:

- 1 Poverty;
- 2 Language;
- 3 Isolation and distance;
- 4 Family breakdown;
- 5 Lack of services;
- 6 Culture;
- 7 Early ageing;
- 8 Culturally appropriate promotional material;
- 9 Cost of service delivery.

5.1 Poverty.

Unemployment rates as measured by mainstream markers are high in remote Indigenous communities. Until the Commonwealth intervention the CDEP Scheme provides the only real work for most residents. CDEP was a 'work for the dole program' that is operated through community councils. Registered participants were paid \$11 an hour for 20 hours for providing work on the community under direction from the community councils. There were approximately 8,000 participants in the CDEP up until June 2007. CDEP has been phased out with the intervention in most Top End Communities over the last twelve months. A few

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participants have received 'real jobs' at award rates of pay. Information is scarce as to the numbers involved but we believe the number of these 'real jobs' is less than a fifth of the previous CDEP positions. Those who were on CDEP are now in receipt of Jobstart payments.

Indigenous carers can theoretically receive Carer Payments and Carer Allowances. Due to language difficulties, lack of information and inability to access appropriate people to sign the application forms, and the overly complicated nature of these, there is a low take up of the benefits. Carers NT has regular contact with over 1,500 carers on Indigenous communities. We are not aware of a single one of these carers receiving the Carers Payment and only a handful receiving the Carers Allowance.

5.1.1 A Carers Tale- Jenny Baird

Jenny Baird is a lecturer in education at the Bachelor Institute of Indigenous Tertiary Education in the Northern Territory. Jenny is not Indigenous. She cares for her husband Warren who she met and married while she was working on Groote Eyland. Warren is indigenous; he suffers from a debilitating neurological disease called Machado Joseph's Syndrome (MJS). Jenny provided in home care to Warren for over 20 years before he was placed into a nursing home. Jenny and her two children, both in there early twenties, live in fear that the MJS will be passed on to the children. Jenny knows that this will face her with the agony of watching the slow physical decline of one or both of her children and the very real prospect of another twenty to thirty years of care.

Jenny has a Masters degree yet needed assistance from Carer Association staff to complete the application forms for a Carers Payment/ Allowance provided by Centrelink. She describes the stress of dealing with the bureaucracy of Centrelink as 'worse than caring for Warren'.

5.1.2 A Carers Tale – Josephine Warlapinni

Josephine Warlapinni lives in the community of Milikapiti on Melville Island. Josephine is 27 year old and the mother of two beautiful children, Sharna who is ten, and Joseph who is eight. Josephine, Sharna and Joseph live with Josephine's mother, Annalisa.

Sharna suffers from profound physical disabilities associated with cerebral palsy, she cannot walk or talk, is peg fed and is incontinent, but is described by all who meet her as 'happy and bright as a button'. Joseph has ADHD.



Annalisa and Sharna in her pram.

Recently Josephine was given the Carers Allowance by Centrelink, but not the Carers Payment. Josephine has been a carer for ten years. Her previous applications for a Carer Payment and Allowance have been rejected because of 'lack of 100 points of ID', despite the fact that she has a Commonwealth Health Card. On this occasion one of the Carer NT Staff spent considerable time getting Josephine's Birth Certificate and assisting her with the application forms. We have no idea why her application for the Carers Payment was rejected. Josephine and Annalisa speak English well and are well educated, unlike a lot of indigenous Carers on remote communities.

This year has been a big one for the Warlappini family. For the first time Sharna has been provided with an electric wheel chair, (she was previously confined to a pram). She is now able to communicate using a Tango electronic communication device. The Wheel Chair and the Tango were providing by fundraising from the Variety Club, again after Carer Association intervention. Previously she had been measured for a motorised wheel chair and other equipment by the Northern Territory Department of Health and Community Services. The family were then told

that they would need to pay \$12,000 for the Wheelchair and \$13,000 for the Tango .Sharna needed the Tango so she can communicate and do her schooling. Sharna attends school every day with her grandmother Annalisa who is her Inclusive Support Assistant (ISA). Joseph unfortunately is often too disruptive to attend or stay at school. An indication of the impossibility of paying the price required is provided by the families response when asked to provide Carer NT staff with a 'wish list' of equipment to assist in caring for Sharna. They listed two items, a bed with a mattress (Sharna slept on a mattress on the floor and was getting heavier to lift from this position) and a 'boomerang pillow' so she could be propped up in bed or in a chair.

Recommendation 1

Centrelink be instructed to provide adequate and appropriate assistance to carers to ensure that carers are able to access the Carer Payment and Carer Allowance despite the carers difficulty with language, literacy, isolation and cultural background.

Recommendation 2

Centrelink be instructed to simplify application forms for Carer Payments and Carers Allowances so that carers who are already under stress can complete these forms.

Recommendation 3

Funding is provided to ensure that adequate equipment is provided to allow carers to provide care for their care recipient safely and with dignity. That this funding includes resources to repair and maintain equipment.

The poverty level on these communities is exacerbated by high cost of living. In Darwin the cost of food is at least 25% higher than other capital cities. (1). The cost of food in remote communities is conservatively estimated at double that of Darwin. Food needs to be bought daily as most people on remote communities do not own

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refrigerators or stoves (food is general cooked outside on a fire). Social Security payments are the same across Australia.

Recommendation 4

The cost of transport of fresh food and vegetables to isolated communities with high levels of unemployment be subsidised by the Federal Government.

The poverty cycle is aided by extremely limited access to housing. The housing that is provided is overcrowded (particularly during the wet season during which time 20 people can share a two room house). Crowding and the associated noise and disruption makes caring for a person with a disability, chronic illness or frail aged very difficult. Added to this is the lack of facilities that are taken for granted in most places, on occasions the only clean water is provided by a tap near the house. Imagine the difficulty in cleaning linen etc if the care recipient is incontinent. Very few carers have access to a washing machine. Carers with disabled recipients have a long wait to get ramps and rails through community housing organisations.

Recommendation 5

Adequate housing be provided on indigenous communities and this housing is modified to allow care to be provided safely and with dignity.

5.2 Language

Amongst the people of Aboriginal descent there are at least 40 languages spoken. English, particularly for people living on remote communities, can be a third or fourth language. According to the ABS (2003) (1) of the 50,000 Indigenous people who speak 'language' at home in Australia, 30,000 live in the Northern Territory.

The result of these language issues can be dire for carers and care recipients. Medical care is almost always provided in English. The language difference, combined with a desire of 'of being shamed' by asking questions leads to misdiagnosis and misunderstandings about treatment. Aboriginal understanding of the source and treatment of disease that does not necessarily comply with the 'scientific approach' that is the basis of western medicine further exacerbate this.

5.2.1 Carers Tale - Bernadette

Bernadette has been the carer for her husband Gregory at Port Keats/Wadeye for 9 years; he has a number of health problems. Bernadette and Gregory speak Mirrinpatha and have had little contact with life outside of their remote community which is cut off by the wet season for 6 months a year. They, like so many other people on remote communities, have no vehicle so very rarely leave their communities. In 2007 he was medivaced, with gangrene in both legs due to diabetes, to Darwin Royal Hospital then to Adelaide Hospital which is the closest medical facility for major operations. Bernadette had to fly to Darwin at the cost of \$375 one-way then organise a flight to Adelaide and accommodation. Without Carers NT to act as an Advocate and speak for them to organise a liaison person to help them in Adelaide, Bernadette would not have been able to be near her husband while his legs were amputated. Hospital is a strange and frightening place at any time, but far more frightening if no one speaks your language and you have not been exposed to a city environment

Recommendation 6

Adequate trained interpreters to be made available to support carers in their dealings with medical and welfare service providers

5.3 Isolation

Indigenous communities are small with a population from 50 to 3500 people and are a long way from anywhere. In the Top End of the Northern Territory a number of communities are simply inaccessible by road for 5-6 months of the year due to torrential tropical rain and associated flooding. During this time travel is restricted to the air, which is expensive. For example the return flight to Maningrida (300 km from Darwin) is \$ 515 compared to a return flight to Adelaide (3,000 km) of \$ 600

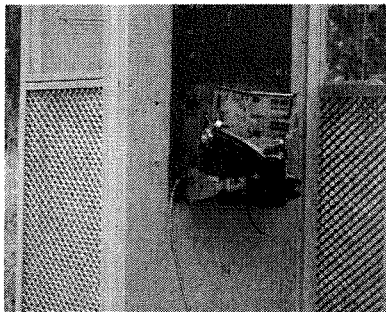
Most Indigenous families would love a 'four wheel drive'. Contrary to myth perpetrated by some, very few have access to such vehicles (indeed any vehicle). There is no public transport on, or to, communities and getting around within a community is generally by foot, which is difficult when their care recipient is in a wheelchair or on a walking frame. Carers find lack of transport a particular problem especially getting to the health clinic and community store. Research carried out in Alice Springs in 2007 by NT Shelter found that even in urban settings bus routes seem to bypass the 'indigenous communities'.

5.3.1 A Carers Tale – Daisy

Daisy lives at Peppimenati. Daisy is a small woman who is over 50 years of age. She cares for Otto, her husband of many years. Otto was seriously injured in an automobile accident seven years ago. Otto is described as a 'big man'. Daisy and Otto live on the wrong side of the Moil River. We refer to her location as "the wrong side" because it is a two kilometre walk to the Health Clinic. Daisy completes the trek often pushing Otto in a wheel chair. There is no other form of transport available in the community other than the community ambulance. The ambulance is on the 'right' side of the river. There is no phone to call for this support. Remember please that there are no sealed footpaths on which to push the chair, and at night there is the ever present danger of crocodiles and buffalo.

Recommendation 6

Service delivery agencies operating on Indigenous communities are provided with funding to provide adequate transport to allow the service to be delivered in a culturally appropriate manner. A vehicle to pick up recipients to go to and from the Day Centre, the Clinic and the store would be a huge bonus.



The town communication centre

Remote communities are difficult to service. They are reached usually by four-wheel drive or by air. The road option takes time, the air option is expensive. Most contact to the Carers NT by carers is through health centres and by telephone. The telephone system can be very problematic. Many carers have only limited access to a phone to make outgoing calls, and often, no access to incoming calls. There is usually only one solar powered public phone on a community often not in working condition.

As mentioned earlier, until recently the only respite that could be provided was to fly the care recipient into Darwin and place her/him into a nursing home. Carers, the wider community and the care recipient resisted this option. When it was used, it often resulted in inappropriate placements such as young men suffering petrol sniffing induced dementia being placed in an aged care facility.

Over the last few years the Carers NT organisation has developed the Troopy Program (outlines above) using funding from a pilot funded by the Department of Health and Ageing to develop a 'responsive respite program'. In addition, some of the larger communities have developed community based aged care programs using the Commonwealth Government's Flexible Aged Care Funding. These services are much appreciated by the few communities on which they exist.

5.4 Family breakdown:

Family breakdown is an issue for all carers. In indigenous communities a malaise arising from hopelessness, that afflicts many, intensifies this process. This is demonstrated by breakdown of the rigid family structure as young men and women 'get on the grog', kava or other drugs. On some communities there is a high level of petrol sniffing amongst the young.

One community worker estimated that on her community 30 % of the male population is in jail or in Darwin (on the grog) at any one time. Many young men see jail as a 'rite of passage' as well as a place where they get three meals day and have a bed. Substance abuse often leads to family violence, mental health issues or child neglect.

Suicide rates are high. The first 6 months of this year there were 30 attempted suicides with 3 succeeding in Nauiyu out of a population of less than 300.

Care is being provided increasingly by the 'grandmother' generation who are sandwiched between providing care for grandchildren and for older relatives. When these women get to the point of needing care, there is often not enough family structure remaining to provide it. Again this is not an issue only in indigenous communities, but is intensified by the other factors mentioned in this paper.

5.4.1 A Carer Tale- Margaret and Farain

Margaret is a proud and independent grandmother from Croker Island. She cares for five grandsons and her husband who is suffering from dementia.

One of the grandsons, Farain, is 15 years old. He suffers from intellectual/physical disabilities. Never the less he completed primary school. There is no High School on Crocker Island, let alone a school which caters for older children with a disability. Rather than see Farain

sit and do nothing' Margaret moved herself and her five grandsons to Darwin so that Farain can attend a 'special' school. The first year in Darwin Margaret and the family lived in a two room flat; they were then allocated a house from Territory Housing. All of the children attend school everyday. Margaret is cut off now from her country, her family and her community. She is routinely 'shamed' as her husband wanders the suburb asking strangers for money for grog, as extended family members take it for granted that they can live at her house in Darwin. Margaret finds it difficult to maintain the yard of her home having no access to a vehicle, mower or trailer, yet she makes the sacrifice despite these challenges so that Farain can 'learn things'.

Recommendation 7

That carers providing care for multiple recipients are paid a Carers Allowance for each of the people they care for.

5.5 Lack of services:

In many communities there are no services other than a Health Centre, which in most cases is staffed by nurses or aboriginal health workers. Staffing these centres is a continual difficulty as there are high rates of staff turnover. Limited HACC services are available on the larger communities; in smaller communities there are often no services.

The brokerage model, that is part of respite services offered to carers throughout Australia, does not work well as there are, in many cases, no services to brokerage. Equipment for those with disabilities is hard to come by and when it breaks down, often through lack of maintenance, is not replaced.

5.5.1 Carer Tale - Ester and the' Strong Women'

In Nauiyu/Daly River there is a HaCC service, an aged care manger Ester and 3 excellent local aboriginal staff. Ester has lobbied for two years to get a room or house to set up as a day centre for her 30+ clients to no avail. This room would give her staff the facility to prepare meals, wash clothes and linen and provide respite. Because there is no room, The HACC meals are provided by the Daly River Hotel several kilometres down the road at the cost of \$12.60 per plastic container. This food is usually the type of food that the aged clients don't find palatable.

'\$12.60 per meals – 30 clients – HACC money gone.'

In Palumpa/Ngmarriyanga a group of aboriginal women aged between 30 to 70 years calling themselves "The Strong Women Group" have lobbied for 4 years to get a HACC service going in their community. They have a building with power, water, stove, fridge, shower and toilet but cannot get funding for training or to get it up and operating. They are told that the 18 recipients in this small community are not sufficient to receive HACC funding.

Recommendation 9

Each substantive community is provided with a day respite facility so that carers can have a rest. These facilities do not have to be 'flash'. A room with mattresses, water, shower, washing machine and cooking facilities will be adequate. They will need to employ a person to provide the respite care, probably a person from outside the cultural group.

5.6 Cultural issues:

In remote communities there are very clear understandings of kinship and tribal law that applies to issues such as who can, and who cannot, provide personal care, even who one can and cannot speak to, or look at. Arranging services then, is made even more difficult when these cultural requirements are taken into account. Certain people are not culturally appropriate to provide care or even enter particular houses.

In a culture based upon sharing resources it is difficult, if not impossible, for people to refuse assistance to certain relatives when asked. When this positive cultural trait is confused by alcohol, drugs or family breakdown it puts those who take the responsibility to provide the care in difficult circumstances as they are 'humbled' for food, money, and accommodation.

Indigenous culture is absolutely associated with the land that is owned by the various groups. This connection inculcates the very essence of the people who believe that they belong to the land, rather than the land belonging to them. This connection is such that care recipients do not want to be taken from their land to attend hospital or access respite outside of their country. Older people are terrified that if they are placed in a nursing home in one of the urban settings, to provide their carer with respite, they will die away from their land. For example, out of 57 carers registered on one community only 5 care recipients agreed to access respite by coming into Darwin.

5.6.1 Carers Tale – Chrissie and the 'Troopy'- an idea that works

Chrissie Nichols is the Coordinator of the three on-community respite programs operated by Carers NT.

These programs include :

The 'Troopy' Program;

The Remote Respite Camp Program; and the new

Mental Health 'Troopy' Program.



Chrissie and friend

Chrissie is absolutely dedicated to providing support to carers living on remote communities. Under her management the program has worked and now provides a model which shows hope for the future. Chrissie's work is ground breaking.

The Troopy program provides culturally appropriate respite to Carers and their family without sending the carer or care recipient away from their community to Darwin, Katherine or Alice Springs. This program works with existing supports and by identifying a responsible service provider on the remote aboriginal community who knows the Carers and recipients usually the Health Clinic or Aged Care program. It then provides them with a Toyota Troop carrier, fuel and camping/fishing gear for 4 to 6 week periods. This service provider on the remote community then coordinates the program to the best suit their community.

These programs empower the Carers and the community as they decide what is the best forms of respite for them individually and as a community, and raises the Carers profile in their own community because they get to go out bush or to town in the Carers NT Troopy.

Because of the national and international recognition of the success of the Troopy program, we now have the Mental Health Troopy program, which runs along the same lines but is more aimed at providing respite to family Carers of people with mental health problems.

The Remote Respite Camp Program is a hands on program for aged care recipients. Carers NT staff go to a remote community that doesn't have a respite centre and set up a tent respite centre out from the community in the aged recipient's favourite camping spots. This allows the recipients' family to be able to work and do other things for that two weeks. It is a good break for everyone, and has a lot of long term positive outcomes. During the two week period two of the Remote

Respite Team provide care: with meals, personal care and culturally appropriate outings daily, usually to gather bush tucker.

5.7 Early aging:

The death rate among Northern Territory Aboriginals is 3 times greater than for other Australians, worse than indigenous people in other developed countries (3)

The life expectancy of an indigenous male at birth in the NT in 1999 was 60.3 years (3). The life expectancy of a non-indigenous male born in the NT in the same year was 76.6 years. This difference does not mean that there is less need for aged care. Aging is advanced, in recognition of this, HACC services are available to the general population at age 65, and for indigenous people the age is 50 years.

An indication of the health situation for indigenous carers is seen in the figures for hospitalisations per thousand population in the year 2000. For non-indigenous Territorians 180, for indigenous 600. There are very high levels of diabetes, kidney failure, circulatory and respiratory diseases (5).

Unfortunately there is no information available as to the number of indigenous carers that are living on remote communities. These are truly hidden carers. Our experience suggests that the proportion of the community providing care would be similar to the wider population, that is about 12%. The difference is that carers provide care for a greater number of care recipients.

5.8 Culturally appropriate promotional material:

Glossy brochures and material with a great deal of written information are not appropriate. We have come increasingly to the belief that the best form of education is in 'language', using either indigenous radio or locally produced TV. Videos are useful, however they date rapidly and quickly become bookends. There is some exciting new software being developed by the NT Department of Health and Community Services that seems to provide the opportunity for new use of computers to allow information to be provided on the ground in a fun way.

In our mainstream communities service delivery agencies often bemoan the fact that people do not identify with the term 'carer' (6). There is no word for 'care' in any of the top end indigenous languages- it is simply something that is done.

5.9 Cost of service delivery:

The Manager of the Top End Commonwealth Respite and Carelink Service, which provides services to the top 1/3 of the Territory including 70% of its indigenous population, explained the cost of providing respite to carers living on remote communities using the following example.

5.9.1 Carers Tale Jane and Fred

'Jane, the mother of a 6-year-old daughter with profound physical and intellectual disabilities, and who was 'peg fed' got to the point that she needed respite. The only option that could be found was to bring the child into Darwin and have her looked after on a 24 hour a day basis by support staff. The cost including transport for the child, a travel escort, accommodation and care, \$10,000.'

After struggling for years and experiencing family breakdown the carer of Fred, an old man suffering with dementia and respiratory ailments, needed a rest. Fred was brought to Darwin and placed in an indigenous nursing home. Because of his illness a pressurized plane was need and chartered, at the cost of \$1,100 one way, adding over \$2,000 to the cost of the respite than would have been the case in an urban setting.

Frankly the funding of services on a population basis is unfair to service providers and ultimately to all carers in a region attempting to provide services to remote community carers as money is eaten up very quickly in providing transport, accommodation and escorts. Nursing home respite beds suitable for an indigenous recipient are very limited.

Recommendation 10

Service delivery agencies providing support to carers and care facilities are adequately funded by all Departments to ensure that appropriate services can be put in place.

6. A Desperate Need for Research

Carers NT believes it provides quality services to carers. This belief is based largely on feedback from clients and other service delivery providers. However we are, like all other providers, hampered by the almost complete lack of objective research into the long and short term outcomes of our interventions. We would love to know, for example, whether short term respite is more effective than long term respite; What impact does a carer taking respite have upon the care recipient and the carer? What is the best way of providing services- face to face or by telephone? How can we better use technology and how does its use effect the wellbeing of carers? What new research in other fields may be able to be used to assist carers?

Certainly there is considerable research into the financial, physical, mental, social and relationships impact of providing care. Most of this indicates that the impact is negative. Amongst the most recent example is the type of research is the 2007 'Australian Unity Wellbeing Index Survey 17.1' which reported on a survey of over 4,000 Australian carers. The findings were astonishing, they included:

- Carers have the lowest collective wellbeing of any group yet discovered by the survey;
- Carers have an average depression rating equivalent to that of moderately depressed;
- Female carers have lower wellbeing than male carers;
- In the general population the wellbeing of people who are separated or divorced is some five points below the general population. The process of caring depresses these by a further 16-19 points;
- A total of 20.6% of the carer sample are unemployed;
- For carers who are employed, over one third have a fear of losing their job;
- Carers are highly likely to carry injuries and this is associated with reduced well being;
- Carers tend not to seek treatment for themselves because they do not have the time or cannot afford the treatment;

Carers NT- Submission to House of Representatives Family and Community Committee on the needs of Carers.

- Household income is a double jeopardy for carers. Their general household income is lower than is normal within the general community and their wellbeing is more depressed due to lower income than the normal community;
- Wellbeing decreases linearly as the number of hours spent caring increases;
- Primary care responsibility for any time per day is extremely damaging to wellbeing;
- Caring for adults imposes less of a burden than caring for disabled children;
- There is no evidence that carers adapt to the situation when caring continues beyond two years; and
- High satisfaction with leisure is more strongly associated with carer wellbeing than satisfaction with carer hours.

Carers NT are raising this issue because we pride ourselves on wanting to operate on an evidence based paradigm. We are in the process of scoping the possibility for us to join with an appropriate tertiary institution to establish a Centre of Excellence in Carer Service Delivery. We believe that the case for the need for carer support has been proved, what is now required is evidence based interventions.

Recommendation 11

The Committee recognise that research into most effective forms of service delivery to carers is part of any consideration for the future needs of carers and that adequate funding and support be provided to allow this form of research to be undertaken.