Submission No. 179

Submission to the House of Representative Committee on Aging from NT Carers Association Inc

Mr. Chairman, Honorable Members

We are here as representatives of the NT Carers Association. We are also here as professionals in service delivery to unpaid family carers in the Northern Territory, which by its nature leads a perspective on some issues that may be a little different.

Let me introduce our group

Leonie Simmons is the Manager of the Top End Commonwealth Carer Respite Centre. Leonie comes from a professional background in aged care nursing and management including a period setting up and operating aged care services on an indigenous community. She is a Member of the Centrelink National Carer Advisory committee. Her current position includes oversight of services providing respite services to an area that includes 70% of the population of the Northern Territory. This includes operation of innovative respite options to carers on Indigenous communities.

Janelle McKell is the manager of the Northern Territory Commonwealth Carer Resource Centre. Janelle is a trained Social Worker and has worked with carers for the past four years both in direct support delivery and in education and training of service providers on carer related issues.

I am Garry Halliday. I am also a trained Social Worker and hold the position of Executive Director of the NT Carers Association. I am a family carer, and have been the recipient of care from my family when I suffered from a debilitating illness. I am a Member of the Carers Australia Executive Directors Forum and a member of National Carers Voice. My personal interest is in the psychological impact of long term care provision on carers.

We are not academics, demographers or policy writers, therefore our short presentation takes it for granted that the aging of our population and the general issues that arise from it have been addressed elsewhere. Certainly some of these issues were addressed extremely well in the written submission made to this committee in 2003 by Carers Australia.

Our plea to you is that you, in your deliberations, take the impact of provision of unpaid family care on the care providers into account.

Bringing the perspective of the family members and friends who provide in home care for the frail aged, the disabled and the chronic ill is radically different from the perspective of the 'medical model' with its focus on provision of service to the 'patient'. The medical model is the pre- eminent one today. Too often the family carers, who statistically provide 75% of all care in our community, are treated as 'supplicants' to do the bidding of health, allied health and health administration professionals. If they do raise concerns they are often dismissed as 'nuisances'.

Lets take just a few moments to clarify our vocabulary and the NT experience. In the context of this presentation, and in our work Family Carers are:

> *parents, children, partners, other relatives and friends who assist with a variety of personal care, health care, transport, household and other activities. Primary carers play a key role in caring and assist with communication, mobility and self-care.*

The population of the Northern Territory is 190,000, of which 25-30% (50,000) are indigenous. This population is spread over a land area of 1.35 million hectares although 71% of this population lives in the 'urban' settings of Darwin (environs) (107,000), Alice Spring (26,500), Katherine (9,000) or Tennant Creek (3,000). There are 16,000 indigenous people living in these 'urban' settings, i.e. 32% (16,000) of the indigenous population. The remainder live in small towns or 'communities', many of which are on land owned by the Aboriginals.

Based upon the latest figures of the Australian Bureau of Statistics (1998) it is estimated that their are 24, 523 carers in the Northern Territory. That is, about 13 per cent of the population of the Northern Territory have caring responsibilities. Of this number, 4,700 people were primary carers. These figures almost certainly under represent the actual number of carers due to a number of issues including the elapse of time since they were collected and the high percentage of the population that is indigenous. The high rate of morbidity on aboriginal communities indicate that the percentage of carers on these communities may be up to three times that of the general community (Markey, 1997). We estimate that there are 8,000-10,000 indigenous carers in the Northern Territory all of whom have similar issues as the carers in the wider community; these issues are intensified by the multiple lenses of:

- Isolation;
- Poverty;
- Language;
- Lack of services;
- Family breakdown; and
- Cultural confusion.

The NT Carers Association is a community organization dedicated to community recoginition of the role played by unpaid family carers; and provision of the highest quality services to these carers and associated individuals or groups throughout the Northern Territory.

To achieve our aims the Association uses multiple approaches including:

- Direct service delivery;
- Community Development; and
- Involvement in public policy formulation.

We look forward to a time when unpaid family carers and associated individuals and groups are recognized as an important element within our community, and have access to timely, seamless and appropriate support services which are delivered in a respectful manner.

The NT Carers Association Inc considers itself to be the peak carer body in the Northern Territory. We are affiliated with Carers Australia.

There is no doubt that the aging of our population generally will place an increasing demand on the need for carers. Some will say that the provision of such care is, after all what a family should do. With respect, we believe is a view of society that is out of date. It is a view that has been called 'unethical' by the World Health Organisation. Changes in society structure do not allow families to provide care over a long period without profound impact on the care providers. These impacts include negative impacts upon physical and mental health, family relationships, life possibilities, and lead, too often, to poverty. It is the carers in this situation right now who are our daily 'work'.

The challenge for the future is to recognize the role of those who choose to be carers as an important part of the health system. We believe that this requires adoption of a formal carer policy by all levels of government that provides them with rights, and identifies the communities and the Governments responsibility to provide adequate support in a range of areas including; involvement in case planning, provision of appropriate equipment, adequate respite and adequate financial support. As part of this policy the need to provide adequate ongoing education to the community about carers and carer issues must be addressed. This should be through all levels of schooling and extend to professional training.

You will note that we feel that these services should extend to those who 'choose to be carers'. This choice must be freely taken with a clear understanding of the rewards and the possible negative implications. This means that other accessible and affordable alternatives must be available and that when the decision to provide care is taken that services promised are available in a timely manner. 'Welcome to the waiting list' is not acceptable, but is the reality for too many of our clients.

Current and government policy for community care seem to be based on the belief that there will be an endless supply of carers. We suggest that this is not the case. The increase in the prevalence of single parent families, the fact that woman are delaying starting families, the economic imperative for many families to have two incomes to meet large mortgages combined with break down of cultural imperatives to provide care to family members support our apprehensions about the availability of an adequate pool of carers in the future.

In a Northern Territory context the special needs of aging people on indigenous communities also needs to be taken into account. Currently there is a high birthrate on indigenous communities. However, the cultural breakdown involving alcohol and other substance abuse, combined with poverty and high morbidity is of serious concern. If the situation remains as it is, early onset of age related illnesses will continue and the supply of able carers will be further depleted.

In addition to the above issues we believe that some of the current issues that are continual difficulties for carers point to improvements that are needed as the number of family carer increases as it must.

- Seemingly good policy decisions such as the EACH scheme need to be managed in such a way that they enable people to stay in their home without causing greater grief than existed before. The rules regulations, exclusions and exemptions make this scheme almost unworkable for some family carers, who after all, are the ones that provide most of the service.
- Policies should be in place that endeavour to keep carers in the workforce rather than making this difficult or impossible. Current rules as to means testing of services based upon spousal income are forcing our clients to give up work, or break up marriages to maintain access to health care cards.
- Respite and support options must be culturally appropriate and available when the carer needs the service.
- If the Centrelink experiment for providing financial support to those who are needy is to be maintained it needs to be adequately funded to provide professional knowledgeable services every time, rather than a service based upon the luck of who happens to be behind the counter when Carers attend. Our Carers should not have to sit on the end of a phone for extended periods of time to then be provided with the wrong information.
- HACC services need to be adequately funded to provide services when they are needed, a trained workforce that is adequately paid for what they do should provide these services. This is not the case at the moment.
- Our clients, and the people they care for need a health care system from which they can get affordable treatment, when it is needed. This is not the experience of many of them at the moment
- An aging community means that there are an increasing number of aging carers. These people need to assured that adequate services are in place to provide ongoing care if they happen to become ill or die. This is not the case at the moment.
- Carers should be forced to continue providing care simply because there is no alternative. For many that is not currently the case.

We urge you not to fall into the trap of considering family carers as an unlimited and free workforce. This will lead to personal and systemic disaster.

It is almost certain that everyone in this room will, at sometime, experience being a family carer or receiving care from a family carer. It should be an experienced that is special and positive to all involved. Unfortunately, for many of our clients, this is not the case. We hope that it will be better in the future.

Thank you for the opportunity to raise these issues. We are happy to clarify any of the points.