



COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

**HOUSE OF
REPRESENTATIVES**

STANDING COMMITTEE ON AGEING

**Reference: Long-term strategies to address the ageing of the Australian population
over the next 40 years**

TUESDAY, 3 FEBRUARY 2004

DARWIN

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**HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON AGEING**

Tuesday, 3 February 2004

Members: Mr Cobb (*Chair*), Ms Hall (*Deputy Chair*), Ms Corcoran, Ms Ellis, Ms Gambaro, Mr Hartsuyker, Mr Hunt, Mrs May, Mr Mossfield and Mr Tony Smith

Members in attendance: Mr Cobb, Ms Corcoran, Ms Hall, Mr Hartsuyker and Mr Mossfield

Terms of reference for the inquiry:

Long-term strategies to address ageing of the Australian population over the next 40 years.

WITNESSES

ASCHE, Dr Leila Valerie, AM, Board Member, Council on the Ageing (NT); and President, Country Women’s Association (NT)	757
BARRAND, Mrs Phyllis Johnson, President, Council on the Ageing (NT)	757
COTTER, Ms Philippa, Senior Aged Care Policy Officer, Aged and Disability Program, Northern Territory Department of Health and Community Services.....	747
GWYNNE, Ms Kylie, Director, Aged and Disability Program, Northern Territory Department of Health and Community Services	747
HALLIDAY, Mr Garry Stephen, Executive Director, Northern Territory Carers Association Inc.	766
JEFFERY, Mrs Rosemary, Director of Nursing, Terrace Gardens, Uniting Church Frontier Services.....	775
LOWE, Dr Michael Peter, (Private capacity).....	786
MAHAJANI, Dr Sadhara Arun, Geriatrician, Aged Care Assessment Team	786
McKELL, Miss Janelle Lisa, Team Leader, Carer Services and Information, Northern Territory Carers Association Inc.	766
MILLER, Ms Carole Helen, OAM, Executive Director, Council on the Ageing (NT)	757
PHILLIPS, Mrs Caroline, Director of Nursing, Juninga Centre; and Manager, Tracy Aged Care, Uniting Church Frontier Services	775
POOLE, Mrs Jane Elizabeth, Care Coordinator, Salvation Army With Care Program.....	797
RATAJEC, Mrs Judy, Coordinator, Territory Older Persons Support Services, Uniting Church Frontier Services	775
SIMMONS, Mrs Leonie Margaret, Respite Manager, Northern Territory Carers Association Inc.	766

Committee met at 9.01 a.m.

COTTER, Ms Philippa, Senior Aged Care Policy Officer, Aged and Disability Program, Northern Territory Department of Health and Community Services

GWYNNE, Ms Kylie, Director, Aged and Disability Program, Northern Territory Department of Health and Community Services

CHAIR—I declare open this 15th public hearing of the House of Representatives Committee on Ageing as part of our inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years. The public hearing that we are undertaking is focused at the moment on remote, rural and Indigenous aspects of ageing. Today we have six witnesses, from the Northern Territory government through to locally based organisations and individuals working with the aged, particularly in the health field. Each witness has been allocated, roughly speaking, about a five-minute opening statement and about 35 minutes of questions from us to you, our general discourse.

I call the first witnesses, who are from the Aged and Disability Program of the Northern Territory Department of Health and Community Services. I welcome you both and thank you for appearing before us. I should warn you—I beg your pardon; I should inform you, not warn you—that these hearings are considered formal proceedings of the parliament, and giving false or misleading evidence may be regarded as a contempt of parliament. That is not a warning; that is information! Now it is over to you.

Ms Gwynne—Thank you. No doubt you have heard much about aged care in Australia throughout the inquiry. Our aim today is not to tell you what you already know. Instead we have provided a written statement of the broader policy and practice challenges, and we believe you have that already. We would like to use our time to share some stories that illustrate the uniqueness of the Northern Territory and how this impacts on the ways that aged care is conceived, delivered and funded. Can I ask you to have a look at the map in the handout that we provided.

I would like to speak firstly about Tennant Creek. Tennant Creek is about 500 kilometres from Alice Springs and over 1,000 kilometres from Darwin. Pulkapulkka Kari, or PPK as it is known, is a beautiful, culturally appropriate, well-run residential aged care facility. Community members bring in bush tucker, camp fires are lit, the residents have pets, and visitors are always very welcome. This service has an operational deficit of some \$300,000 per annum. On your map you will find Tennant Creek about three inches north of Alice Springs. The reason for the deficit is that 15 of the 18 residents are RCS 1 or RCS 2, 15 are Aboriginal, and all residents are concessional and have no capacity to raise a bond. They operate a small laundry and a small kitchen, and that is very expensive on a small scale. There is an insufficient skilled casual work force in Tennant Creek, so often staff are brought in from Alice Springs. That means they have to provide accommodation, overnight allowances and so forth in order for those staff to provide a service.

I would like to move quickly to East Arnhem. East Arnhem is on the far right-hand corner of your map. There is no residential care in the East Arnhem region. All care is community based. This means that the services delivered are innovative, flexible, culturally appropriate and very

remote. We thought it would be appropriate to share some pictures, if the chair will permit us to do that. The laminated photograph is of an ACAT assessment to the south of Nhulunbuy in East Arnhem Land. There is another photo of a meal being delivered through Meals on Wheels in the wet season in East Arnhem. The third photo is of a fantastic service on Groote Eylandt, which we hope we will have an opportunity to speak with you about later. It is an example of very good practice. On the day that we did that particular ACAT assessment in the photo, we prescribed equipment, we checked on a man who had been hit by a car the previous day, we discussed respite care options, we organised care allowances and provided some one-on-one assistance to carers. We saw about 10 aged and disability clients on that day.

Ms HALL—Where are those who require respite care located?

Ms Gwynne—I am about to go on to that. Clients who require residential respite are flown to Darwin. In this particular context, the separation of services to younger people with disabilities and people who are ageing would be inefficient and ineffective. In effect when our staff go out to those remote regions, they provide services right across the spectrum of people with disabilities, including those who are ageing and have disabilities. Getting out to this particular remote community took about an hour and a half each way. This was a relatively short trip; most trips to East Arnhem Land are made by air. To access residential respite care, people are flown to Darwin. For many people English is their third or fourth language and they may never have travelled to a city prior to becoming aged. This is a very frightening experience. Many people have a fear of dying away from their land and their family.

The issues around language and culture are very significant in the Northern Territory. I was out at East Arnhem last week and an elder told me about an elderly woman who was accessing respite in Darwin. She had been patting and pointing to her stomach and gesturing to the staff. They thought she had indigestion, but she was saying that she wanted to see her babies—her adult children—and that she was missing her family. Later on during her respite visit, she was gesturing to her eyes. They thought she had sore eyes and gave her eye drops. In fact, she was just saying that she was very sad to be away from her family and her land. There are significant language and cultural issues. Taking people away from their land in order to access a service has a whole range of issues not only from a service delivery point of view but also from a real human perspective.

Katherine is about 300 kilometres south of Darwin. There is a range of aged care services provided in and around Katherine. However, many of the remote communities are completely inaccessible during the wet season. Aged care services are subsidised financially by the NT government and by service providers. We are in the process of reviewing our service network in Katherine so that we can find ways to look more broadly across the aged and disability spectrum and to plan our service delivery more efficiently around the seasons here, particularly in that part of the Territory and the Top End generally. We find it very difficult to provide services in the wet season, particularly in remote communities.

I want to table another letter, if I may. This time I do have copies. This is a letter from Mr Doug Strain, who heads up Masonic Homes. They have just established a residential aged care facility in Darwin. In that letter he articulates the differences between providing services in the NT and, in this instance, Darwin. He makes comparisons with South Australia, where the bulk of their service delivery is. He makes a compelling case.

To summarise, the NT does not have a metropolitan centre to cross subsidise rural and remote regions. Whilst Darwin is a capital city, the cost of delivering services is very high. Services in Darwin experience viability issues including staffing, supplies and climatic conditions. The NT government and non-government providers subsidise all residential aged care in the Northern Territory. According to the Commonwealth Grants Commission, service delivery costs in the NT are 250 per cent the national average. This is not surprising given that one per cent of the national population is dispersed over one-sixth of the landmass. Twenty-nine per cent of our population is Aboriginal.

The ageing population in the NT is different from elsewhere, and planning for aged care also needs to be different. Our services are innovative and creative—in fact we think we have some lessons that we can share elsewhere in terms of providing very cost-effective services in remote regions. Our staff travel immense distances to visit their clients and have a sound cultural competence and understanding, but we do need a broader community services approach and fewer program boundaries. We need flexible, community based programs that cater to the culturally specific needs of our population. We need funding formulas that reflect our remote, and very remote, context.

CHAIR—Thank you very much for that, Ms Gwynne. We have heard over the last day that a lot of people retire and leave the Territory. Do you find that in Darwin in particular your aged care services do not have more call on them all the time? Is the number of people who are retiring in Darwin increasing, or is it stable?

Ms Gwynne—It is little bit like the chicken and the egg, isn't it? I will come to the figures in the moment. If there are not enough services or infrastructure for people to remain, they leave—and because they leave, there is not the waiting list. I think that there is that cycle across our program.

CHAIR—So you believe that it is more because there is a lack of services and infrastructure than because they are transient people who naturally go to other states when they retire?

Ms Gwynne—I think it is a combination of both. I think that we cannot ignore that catch-22. I think it is certainly true that we have a very transient population here. Ms Cotter has the figures.

Ms Cotter—The ageing population is increasing and that is largely at a faster rate than elsewhere. In the last 12 months, the number of people aged 65 and over increased by 4.9 per cent, whereas nationally the rate was 2.2 per cent. So we are getting some accelerated growth. It is never going to reach the same proportion as elsewhere. For a place with a younger age structure that brings challenges to respond to a changing age structure.

CHAIR—We have also heard that the Aboriginal population tend to age earlier for a variety of reasons. Do you have any comments to make about that for the committee and the government to take on board? Do you have any comments to make on that that you think we should hear?

Ms Cotter—I think there is a paucity of serious commentary on Aboriginal ageing. We do not know much about the pattern of Aboriginal ageing. There are some suggestions that the Aboriginal population is not ageing because of the high morbidity, but within that we do not

know about the pattern of need within the Aboriginal aged population. Anecdotally, some people say that the Aboriginal people who survive to old age—over 65—are the survivors who might have better health. But there is no evidence for that particularly; that is just what people see. We have highlighted some of the issues around the population having residential aged care facilities being full of people with chronic diseases in their 40s and 50s. We are yet to address those sorts of issues.

CHAIR—Do you believe that it is being corrected at all and addressed in a general sense?

Ms Cotter—That raises—

CHAIR—Is that too close to being a political question?

Ms Cotter—No. I think that raises the complexity of health across the lifespan and the different intervention points. I am reluctant to speak about the breadth of that. I certainly think that there are some changes particularly in primary care, where we see the interface between aged and primary care as probably more important than, say, the acute aged care interface. There are some changes being made there. Different models such as community-controlled models and so on are being trialled. It is not all hopeless.

CHAIR—In general, what do you think the cooperation between the Territory and the federal government is like on issues like the HACC service? Is it working? Do we need far better cooperation? From your angle, how does it work?

Ms Gwynne—At an officer-to-officer level there is good cooperation, and we share concerns about a range of issues in the delivery of aged care in the Northern Territory. There are some systemic issues that are perhaps a challenge to all of us. For example, funding formulas and the way they are calculated have a very significant effect on the Northern Territory.

CHAIR—Do you want to enlarge on that?

Ms Gwynne—Sure. Philippa has the detail of that. Pulkapulka Kari in Tennant Creek is a 19-bed facility. If it goes over 19 beds, it loses its remote allowance. That would take it back to \$11.82 per day per occupied bed. At the moment, it gets \$19.20 per day per occupied bed. Even the \$19.20 rate does not cover the additional costs of providing services in Tennant Creek.

Let me talk about maintenance at the nursing home. They need a small amount of maintenance but there is no-one in town, so they have to get someone to come 500 kilometres from Alice Springs to do it. We are looking at ways to get better efficiency in Tennant Creek—we are working with the Commonwealth on that—but at that very basic level the funding formulas are hugely problematic. The remoteness of the Northern Territory, the top end of Queensland and the top end of Western Australia provides a whole range of issues, at a systemic level, for delivering services.

CHAIR—Regarding aged care for all the population, do private carers provide a good level of service? Is it well managed? Do you believe it is sufficient?

Ms Gwynne—Do you mean by private providers?

CHAIR—Yes.

Ms Gwynne—We do not have private providers up here. The providers are charities who subsidise those services.

CHAIR—It is the same thing. I mean non-government providers.

Ms Gwynne—They have to come with some backing behind them, in a sense, from a larger organisation, because all the services are subsidised by their host agency. The providers in the Northern Territory are generally very good and very experienced. I understand that you are going to see a Frontier Services service today. They are our most experienced provider across the Territory. They provide services in Tennant Creek, Katherine and Darwin. Overall, they are very good.

Ms HALL—You said in your original presentation that the facility at Tennant Creek is operating at a \$300,000 a year deficit. How do you cover that?

Ms Gwynne—The NT government makes a contribution and Uniting Church Frontier Services picks up the rest.

Ms HALL—Thank you. I wanted that detail for the record. I now want to refer to the letter from Masonic Homes Inc. On page 2 it looks at the RCS classifications. I also note that you say in your submission that the cost of the provision of services in the Territory is 250 per cent of the national average. On these RCS classifications, in the Northern Territory, with remote subsidy, it costs less than in Tasmania and Victoria and just marginally more than in New South Wales, South Australia, Western Australia and the ACT. How do you cope with that here in the Territory and what strategies do you have in place to get around it? Is the strategy more subsidisation by the Northern Territory government and the non-government sector or is there some other strategy?

Ms Gwynne—I think that has to be part of the strategy, but it is not the whole story. There are obviously things that we can do and that we are doing. Because we provide services within our own department, our own staff work side by side with those providers in the community. Finding ways to make efficiencies is high on our agenda. I go back to the example of Tennant Creek and the issues of maintenance, casual staff, laundry and meals. There is certainly some capacity there for the non-government providers to work with the hospital and with other services around running one laundry and one casual pool for the whole town. It is a long-term process to work with the communities and the providers on that issue, but certainly there is agreement that that is what is required. I think the other side of that is about ensuring that those services can maintain their autonomy and the backing they bring with them. For example, if there were to be just one provider, or one pool of funding, in Tennant Creek the financial and social capital that those non-government providers bring with them would be lost, and that would not be what we are looking for. So it is about finding a way of being cooperative and collaborative and making some efficiencies without bringing everyone into the same pot, if you like.

Ms HALL—Thank you. Is that what you mean when you talk about the flexibility of delivering services?

Ms Gwynne—I think that the program boundaries between aged and disability—

Ms HALL—Include that, because that was my next question—about the program boundaries.

Ms Gwynne—are a bit of a nonsense here in the NT. In the entire East Arnhem region I have four staff who work for the department in the aged and disability program and provide services right across that region. They link in with all the communities and all the non-government providers. The team leader there also wears the hat of the local area coordinator and the hat of the ACAT assessor. To them it is a nonsense to separate out those particular functions and say, 'We need an aged care person and a disability case manager' particularly when we are going out to remote communities; it is meaningless to them for a white person to come out and say, 'I can only talk to you about disability issues today.' Those program boundaries are very real for us, so we would be looking for a greater level of flexibility in the reporting, the funding and the way that those resources can be utilised.

Ms HALL—That is a very important message for us, I think, to take back and something that as a committee we can look at very seriously. You were talking about Aboriginal ageing and there is very little data available on that. Is any research being done in that area and, if not, what sort of research do you think is needed in that area—longitudinal studies, for example?

Ms Cotter—I think probably the range. Some of it would be drilling down to look at a little bit more of the detail of how that population is changing, and how it is changing in different places. The majority of Aboriginal people in Australia live in urban centres—so perhaps looking at that diversity.

Ms HALL—Is the Territory government collecting any data on it?

Ms Cotter—Not that I know of, apart from our general day-to-day data collection.

Ms Gwynne—Can we take that one on notice?

Ms HALL—I would love that. It would be great if you could come back with some more information for us on that. In the other states that we have been to we have heard that there is quite a shortage of beds within low-care and high-care facilities and also quite a shortage of Community Aged Care Packages, that there is a waiting time and that quite often people who are waiting for these services remain in hospital. Is that the case here in the Territory?

Ms Cotter—We do have a waiting list for each of those places. The preference for community based care means that the wait for CACPs is longer than for the others. The recent opening of the Masonic Homes facilities in Darwin has relieved the pressure of people waiting in hospitals. So at the moment people do wait in hospitals, but it is not as significant as, say, the winter problem in other jurisdictions. But it is mostly to do with the balance of care, I would say, in the Northern Territory: 50 to 60 per cent of people in hospitals are Aboriginal people, whose preference is to be on country, so ticking the high-care residential box is affected by that.

Ms HALL—So the message for us is that in the Territory you need to do things differently. It is a very different population and, as such, the programs need to be designed to meet the needs

of the people of the Territory, rather than the people of the Territory meeting the needs of the programs. Thank you.

Mr MOSSFIELD—On the staffing questions, what percentage of your staff would be Indigenous people?

Ms Gwynne—I would have to take that on notice.

Mr MOSSFIELD—I am asking because of the cultural issues that have come up and because of the need to understand the cultural views of the Aboriginal people. How would your staff become familiar with some of the cultural issues that would be very important in liaising with the Aboriginal communities?

Ms Gwynne—They work very closely with community leaders and respect the rules or the expectations of those communities when they are visiting. I would say that our staff have a very high degree of cultural competence and know their communities very well. In most cases they are very well respected by those communities and are welcomed in a way that I found very surprising. I have only been in the Northern Territory for 3½ months, in which time I have been completely overwhelmed and overawed by the acceptance of our staff into those communities. They may come once a month or every three months to deliver services, but they are known and people know what they do, and they do it in a very respectful way.

Ms Cotter—There are some resources developed—cross-cultural awareness programs and those sorts of orientation things that get people started. But mostly it is done as they go and from working in a team structure.

Mr MOSSFIELD—Do you find that you are able to retain your experienced staff, or do you have difficulties in that area?

Ms Gwynne—I do not know the rate; I can get that for you. There is certainly a short span of time of working in remote communities. If people stay two or three years, that is very positive—particularly in places like Nhulunbuy and Tennant Creek. We often find it very difficult to recruit to some very remote regions. It is a long way from family and home and you need to be a very experienced person to work there. We cannot put inexperienced staff in very remote communities. So finding the right incentives to encourage people to work here is an enduring challenge. I have to say that we find it somewhat easier in coastal regions than in the very centre.

Mr MOSSFIELD—On the funding issue, which obviously is very important, has the government been asked to address that anomaly that you have explained to us about losing the funding if they go over a certain number of beds—over 19 beds? Have you been asked to address that issue?

Ms Gwynne—Can we take that on notice?

Mr MOSSFIELD—Yes. Finally, one issue that came out at other hearings is mental health. Is that issue being addressed at any stage? Is it a problem?

Ms Gwynne—Can you clarify the question?

Mr MOSSFIELD—We have found generally that there are insufficient skilled staff to handle people with mental illnesses. The other illnesses are fairly obvious. Sometimes mental illness is not so obvious.

Ms HALL—The psychogeriatric area.

Ms Gwynne—I guess residential aged care is a small component of our service delivery. I will get Philippa to add to this. In a sense, communities support and maintain a whole range of people with needs within their communities for the most part. We provide some assistance to help them to do that. There is currently a review of mental health in the Northern Territory, but I do not know if the aged took up too much of that review. We could clarify that. The main psychogeriatric services are Darwin and Alice Springs based. There are occasional visiting services to other centres, but that is not common. There are also not good assessment tools. That is a common issue that is raised, particularly for Aboriginal people.

Mr HARTSUYKER—You talked about innovative programs for service delivery. Could you give us a few examples of the types of programs that you were referring to?

Ms Gwynne—I will talk about the service on Groote Eylandt, which is to the east of East Arnhem. A service there has got lots of little buckets of money. It is in a small place called Angurugu. The building there was built with the elders, the community and an architect over many years. In fact, the people whose vision it was have worked for Anglicare for 30 years and raised their own children on Groote Eylandt. Their engagement with the community and with various government departments—and, I might add, with a high degree of sophistication around that—resulted in an incredible building. It has day services and disability services—it is a base for various types of service delivery on the island. It is not providing 24-hour care at this stage but we hope that it will be able to do that down the track. I guess that what makes that service so successful is that the community designed it and runs it. The two people who run the service, if you like, are employed by Anglicare and have a very respectful and integrated relationship with the community there.

There are very few program boundaries, although their reporting is very good, and they operate a very cost-effective service. The people come in with their families early in the morning and will often have a bit of a sleep, some food and spend the day there. As I understand it, there is quite a nocturnal culture. It works very well for the older people and people with disabilities to come in through the day. It is a beautiful service. The building is in the shape of a sawfish. It is designed completely in keeping with the culture there. Every room has two separate doors so that if a poison cousin comes in the person can leave without walking past them. It is amazing: many of the other buildings in that particular town have unbelievable levels of security, and this building has never been touched. It is a very respected building by the community and that is why it works. The lesson it tells us is that it takes time. The people who run that service have lived in that town for 30 years. It is very difficult to duplicate. That is just one example.

Mr HARTSUYKER—Do you have another example?

Ms Gwynne—East Arnhem is a really interesting part of our region. The other issue of interest as to an innovative service model is around a disease called Machado-Joseph disease. That disease is unique to that part of Australia. It clearly crosses the boundaries of the aged and

the disabled in that originally it was just the older people who were getting sick. It is like a wasting disease. It has what is called an 'anticipation effect': each generation—it is hereditary—are younger and younger when they get it. We have a recent diagnosis of a 12-year-old.

Clearly, in a remote area like East Arnhem the way we provide services to people with MJD is irrelevant, whether they are 60 or 16. We need to look at how we manage the services we provide to them right across their health and community services needs. The way we have begun that is by doing a major piece of research into how the community understand that disease and what it means for them. We have found a whole lot of knowledge deficits. We need to think about how we assist them to understand what is happening to some of their families.

The other thing we have found through this research is that even families who clearly understand the genetic nature of this disease have a dual understanding of what is happening. I guess they have a rational view and a spiritual view—an intellectual view and a spiritual understanding—of why particular families and family members are affected. The way we provide services to those families is through the centre on Groote Eylandt. Others who are on the mainland, in East Arnhem, are flown to Darwin. I guess it is about our staff crossing a whole range of boundaries to deliver those services. They interface at the level of primary health. Basic things like bowel and bladder are very significant issues in this particular disease. Why would our staff say, 'I am terribly sorry, you'll have to see the community nurse'? When they are already out there, why would they not begin to address those issues with those particular individuals? And that is what we do.

Ms CORCORAN—It seems to me that the things that are different about the Northern Territory and what you have to do to provide services are related to both the remoteness and the high proportion of Indigenous people in the population here. Is it possible to separate out the things that you have to do because of the high proportion of Indigenous people in the Northern Territory from the things that you have to do because of the remoteness of some of the communities, so that we can transfer some of your experiences to other areas, or are they so interlinked that that is almost impossible to do? Do you have services here in Darwin that cater to European people and Indigenous people that might help?

Ms Gwynne—It is difficult to find the words to say this in a way that does not sound silly. I think that providing services to Aboriginal people is very challenging for European people.

Ms CORCORAN—For what reasons?

Ms Gwynne—Language is one reason. There are things that are different. For example, the new Masonic nursing home out at Tiwi has individual airconditioning in every room, because the European people—the white people—who live there like to have the airconditioning on. For Aboriginal people it is way too cold. You will see the concept of individual airconditioning in our facilities around the place. There is the capacity to have outdoor spaces and for people to bring in bush tucker and for that to be cooked on the campfire and so on. I guess it is about being more flexible in the way you deliver services and looking at what is possible and reasonable. It is about challenging whether a rule is really needed or whether it is just there because our culture tells us that it should be. Cultural competence is really very significant. Aboriginal communities and people will not use services unless they are acceptable or unless they are very unwell. Often, by the time people access these services, they have a higher degree of need.

CHAIR—Thank you very much for that. We might write to you for more information if that is okay. I appreciate your candidness and I thank you very much for being with us today. Will somebody move that we accept both the submission and the letter?

Ms HALL—I so move.

CHAIR—Thank you.

[9.47 a.m.]

ASCHE, Dr Leila Valerie, AM, Board Member, Council on the Ageing (NT); and President, Country Women's Association (NT)

BARRAND, Mrs Phyllis Johnson, President, Council on the Ageing (NT)

MILLER, Ms Carole Helen, OAM, Executive Director, Council on the Ageing (NT)

CHAIR—I welcome representatives from the Council of the Ageing to our hearing today. Once again I must remind you that this is a formal hearing of parliament. If you stray too far from the norm you can be held in contempt, but I am sure that that will not happen. I invite you to make an opening comment.

Ms Miller—The Council on the Ageing (NT) welcomes this inquiry into the long-term strategies to address the ageing of the Australian population over the next 40 years, and particularly the decision of the committee to visit the Northern Territory. COTA Australia has already made a submission to the inquiry. COTA (NT) believes the Northern Territory is well placed to meet the challenges of an ageing population, but there are unique issues and concerns. The figures for senior Indigenous Territorians are cause for serious concern: only some 2.8 per cent live beyond the age of 65. Health remains by far the most important issue identified by all seniors for this inquiry, but for Indigenous Territorians it is nothing short of critical.

While the Northern Territory population continues to have a lower median age than that of other states and territories, we are pleased that the retention rate for older Territorians is constantly increasing. It is less than 20 years ago that June and July were the only months in which Territorians saw white or grey hair. We used to refer to them as the granny months—the months in which the grannies got off the planes to come and visit their grandchildren for a very short time. However, with the advent of reliable and cheaper power, accompanied by the split airconditioner and better medium density developments and aged care, more and more Territorians have opted to stay put rather than continue the traditional age drain to Queensland.

The Northern Territory government's pensioner concession has been another attraction. Arguably the most attractive of such schemes in the Commonwealth, it has made the tyranny of distance more bearable for senior Territorians. COTA (NT) has been serving seniors and their interests since 1969. The Northern Territory government, through the Department of Health and Community Services, provides financial support to assist us in fulfilling our policy, consultation, representation and information dissemination roles. We applaud the policy of the aged and disability program, which maximises community participation for senior Territorians.

Over the past few years, COTA (NT) has divested itself of the provision of several services but it has retained service delivery to the Territory's culturally and linguistically diverse seniors through the Commonwealth government's Partners in Culturally Appropriate Care and the Northern Territory government's Office of Ethnic Affairs. With our small but dedicated staff, individual members play an important role in maintaining and informing the work that we do,

and we cannot praise the contribution of volunteers highly enough. Their input guides policy and priorities.

We took the decision to merge with National Seniors at a national level, and here in the Territory we have already done so on an informal basis. The partnership represents some 1,640 members in the Territory. We have a new strategic direction, which I have listed in our submission. Besides providing a peak body and sound policy advice to all levels of government, we are managing the partnership, establishing and servicing an NT policy council and establishing a presence that is easily accessible by senior Territorians. We are very proud that we are providing a genuinely friendly membership-focused organisation. We have relocated and renovated a home in the city, Spillett House, which we are turning into a one-stop shop for all Territory seniors, in partnership with Darwin Pensioners and Senior Citizens. Our staffing policy is a first for COTAs, and we are proud that it discriminates positively in favour of senior Territorians in our staffing.

We identified the issues and concerns that we wanted to bring to you this morning. On page 4 we list the issues and concerns. Nationally, they are employment, mental health, grandparenting, Medicare, dementia and consumer participation, to which has been added, by our organisation forum at a national level, dementia and access to health and support services. In the Territory, we have identified these issues and concerns at this time: Aboriginal seniors; aged care—home-based and residential; carers; day care and respite care; dementia; dental and oral health; discharge planning; convalescent and palliative care; employment for mature Territorians; ethnic seniors; grandparenting; health services; housing; membership of government committees; the NT pensioner concession; transport; use of medicines; volunteerism in remote communities; and a professional work force in aged care and health.

We have not had sufficient time to prioritise the issues we bring to the inquiry's attention, but we strongly agree that dementia and health and support services, including carers, must be at or near the top of any list of concerns. The common thread through all but one issue is the dire state of many of our senior Aboriginal Territorians. We can only agree with the NT Department of Health and Community Services that improving Aboriginal services health poses the greatest challenge to the Territory.

Mrs Barrand—I have selected two or three points out of the identified issues, rather than going right through everything—the things that to me are vital. At the top of them, of course, is Aboriginal seniors: the carers needed there, the health needs of the seniors within the communities and the difficulties of getting people to go there and stay there. One of the things that increases the difficulty there is that the way of life does not have the concept of volunteering that we have as a community. It means that sometimes, for example, children whose parents do not bother with them very much become the responsibility of everyone or no-one in the community, and that makes it very difficult to look after and bring these children into a good state of youth, education and health. The question of care extends beyond the communities into everybody's lives—day care and respite care. One of the biggest difficulties here is the fact that it is virtually impossible to get immediate day care in one day care facility, and that is one which is run for dementia patients.

CHAIR—By day care, do you mean respite care?

Mrs Barrand—No, day care, where you go in the morning and come home at night. A lot of people have their relative—their mother or their father—living with them, and they sometimes need to get out and go somewhere.

Ms HALL—How many places does that day care centre have, and is there a waiting list for it?

Mrs Barrand—I imagine there would be an enormous waiting list. We would have to take it on notice. I think it only takes about 10 or 11 people, and that is the only one. There is not a day care centre at all for people who do not have dementia. Your mother may be very nice and wonderful to live with, but just occasionally you would like time to go out and do something by yourself. I am speaking personally; I had my mother live with me for a great number of years. It is essential that a person who is caring have some support. You can get respite, but it is only for two weeks. By that I mean that it must be two weeks, if you see what I mean; you cannot say, ‘Can I possibly have Mother looked after for two nights while we go down to the theatre or something?’ That is not possible. Either she goes in for two weeks or she does not. That seems to me to be a very short-sighted policy. However, that is the way it is. Emergencies are not really catered for in that sort of way.

Following on from respite care, we get on to convalescent and palliative care. We have recently been distressed by the fact that the discharge planning system does not seem to plan—at least not very well. We had a lady who was discharged home following massive surgery and was left to go to her own home, which is a two-storey building. The only other person living there is her husband, who is in his late 70s and very frail. That really is a recipe for disaster. If she does not come back to hospital—as I believe she is doing now—then he will, because he cannot cope. This sort of discharge is not reasonable.

I do not like the idea of ‘transitional’ care. Transitional? It is convalescent care. I think if we call it what it is we might get a little more public sympathy towards helping to get it. We are not in a transition from one phase to another; we are going home from hospital. But we cannot go home—we are not well enough—and so we are going into convalescence. Everybody understands that, so maybe we need to look at renaming it with language that people understand. Going on from convalescent care, of course, we have to touch on palliative care. That is non-existent except for a couple of beds in a hospital ward, and, let me tell you, a hospital ward—

CHAIR—Are we talking about Darwin?

Mrs Barrand—Yes. A hospital bed in hospital ward is not somewhere to go and die.

Ms HALL—Chair, is it OK if I ask a question?

CHAIR—I am sorry; I think we are running low on—

Mrs Barrand—I am sorry; am I talking too much?

Ms HALL—No.

CHAIR—But we will have to get on.

Mrs Barrand—Okay. The one thing I would like to add to that is the vision at 8.9 in the booklet. It says:

Providing care for people who are dying and their families is the hallmark of a humane society ...

Remember that people who are dying are not necessarily elderly; they may be quite young. They need somewhere that is like home. People who look after their grandchildren are very often very much disadvantaged. They have all the responsibility but get no recognition or help financially, and I think that should be looked at. The membership of government committees is important. People who have knowledge are often excluded from the membership of the committee because there is a feeling that they may have a conflict of interest. I think that is insulting to professional people, and it is wasting a wealth of knowledge. Surely, you can be relied on to say: 'Look, I can't be involved in this discussion because it's about my place. I can't do it.' But you would not want to lose all that knowledge.

We also need some sort of help in the uses of medications. That could be done by carers who go out to houses, making sure that people understand their medications and take them at the required times. If we do not do that, they either do not take them at all or take them all at once. Either way, it becomes a much more expensive item for the government. The biggest problem of all, of course, is the getting and keeping of staff in the Northern Territory. One of the things that we might even consider looking at is probably old fashioned, but in my day once you had finished a scholarship you might be required to bond yourself to going to a particular place and staying there for a couple of years. If we got them here for a couple of years, we might manage to keep them, because it really is nice living here. I think that has picked out my favourite bits.

Dr Asche—I am involved with the health of Territorians, including Indigenous Australians, and what I see is the very short life expectancy of Indigenous Aborigines who are living in communities. Is not culturally appropriate to call Aboriginal people anything other than 'of Aboriginal origin', but we have a large population in Darwin and Alice Springs who are of Aboriginal descent but in fact look like you and me. They go into our homes for the aged, they access health care and they are eligible for council accommodation, and really I think they need to be excluded from the statistics of Indigenous Aborigines. I do not think that that is happening.

In the communities themselves, there is a large proportion of people with kidney disease. We are slowly but surely providing dialysis units in Aboriginal communities. There is one over now on Bathurst Island, one of the Tiwi Islands. It is managed by nurses who are not Aboriginal or of Aboriginal descent. The dialysis unit that is very near me in Darwin would perhaps have one person out of 20 who is non-Indigenous. A lot of them have come from the communities—as you know, we call the Aboriginal settlements 'communities' up here. They have to leave their homeland and live in Darwin, and they age very quickly and die quickly

So really all I can say is that I have seen the problems of health in Aboriginal communities and the fact that the people in those communities have a much shorter life expectancy than we have. As you know there are very few towns and two or perhaps three cities in the Northern Territory with a reasonable population, and a lot of that population would be made up of people of Aboriginal descent. They live to a great age, and that is because of the health services, the better food and the fact that they are employed. In fact, I go to occasional birthday parties of Aboriginal women who are 80. You do not see any of that in the Aboriginal communities. So I

just feel in a way that our statistics coming from the health department should separate out those communities from our urban Aborigines, who are as white as you and I and should be called 'people of Aboriginal descent'. We no longer say half-caste or quarter-caste.

CHAIR—Thank you. You have probably prompted my first question. What you are really saying is that the figures are not coming out as strongly as they would if you took out the people living in the towns who are only part Aboriginal and live pretty much as everyone else does. Are you saying that if you did that the figures would look a lot worse for the true Aborigines?

Dr Asche—Yes, I guess so.

CHAIR—Is that what you are saying?

Dr Asche—Yes. The previous submission spent a lot of time on the Tennant Creek provision. Was that 19 people? That is not many people, and most of those I think were Indigenous Aborigines brought in from communities. They have had to leave their communities, but you could hardly provide a service within a community of 30 people. Perhaps there has got to be a change in the cultural idea of carers in those communities.

CHAIR—Thank you. That has probably led to another question I wanted to ask. I see here, Ms Miller, that you talk about Territorians aged over 50 years and 45 years. Does that mean that you generally think that there is five-year difference in when the ageing happens?

Ms Miller—The accepted figure is that Aboriginal people age 20 years more quickly.

CHAIR—They age 20 years more quickly?

Ms Miller—Yes, so at 45 they are regarded as aged.

CHAIR—That clears that up. My other question, very quickly, is this: as you are probably aware, this inquiry is not just about aged care; it is also about people's expectations about ageing, quality of life et cetera, beyond actual aged care. I see you mentioned employment. Two of the half-dozen issues you mentioned at one stage are employment and consumer participation. Could you very quickly enlarge on those for me a bit—your thoughts on what older people expect out of employment and what you mean by consumer participation?

Ms Miller—Do you mean consumer participation in decision making? Consumer participation in decision making is what we are all about.

CHAIR—Right.

Ms Miller—I guess COTA is all of that. Are we talking about employment for mature Territorians?

CHAIR—Yes.

Ms Miller—Yes. There is a bit of a problem here, because we proclaim ourselves to be the youngest area in the Commonwealth, with a median age of something between 28 and 29—and

that has gone up in the years I have lived here. I think it was 25 when I first came here. But increasingly we are getting complaints about age discrimination in the Territory, because more and more of us are opting to stay here. As you age here, as you can understand, if you do not have airconditioning, it is off to the coast down in southern Queensland somewhere. But, with split systems et cetera, more and more of us are opting to stay here. This climate does affect you as you age. But, if we are going to stay here, we want to work. We want to work until we are 60 or 65 and, of course, the Commonwealth has told us that it needs us. But there is a bit of reluctance. If you go in for an interview and the person interviewing you is in their 20s, they think somebody in their 50s or 60s is past it.

CHAIR—Is that generally, or by government agencies?

Ms Miller—We have had complaints that it is right across the board. It really needs to be addressed.

Ms CORCORAN—I want to take that thought a little further. We have heard a lot about ageing, the difficulties with aged care and that sort of stuff. I would like to put that to one side for a minute and follow up on employment. We have been thinking about quality of life, healthy ageing and enjoying the more senior years. Clearly employment is one option, but eventually are there issues to do with keeping people occupied, satisfied and still contributing once you have retired?

Ms Miller—We are great volunteers.

Ms CORCORAN—Are there gaps or things that we could recommend in this report to help that aspect of ageing?

Ms Miller—We do examine volunteering but we have focused in the remote communities on the lack of volunteering and the lack of a volunteering culture.

Ms CORCORAN—I want to take a positive view.

Ms Miller—Territorians are phenomenal volunteers—it is just incredible—and COTA is an example of that. We could not exist without the volunteering input that we have.

Ms CORCORAN—So for the Territorian who is going to retire at 60, 65 or 70, who is still fit and healthy and all the rest of it, are there plenty of things to do?

Ms Miller—There really are plenty of things to do: recreation and leisure.

Dr Asche—We have the usual things like U3A, Probis and Rotary—it is just endless.

Ms Miller—Sports clubs.

Dr Asche—There are sporting clubs, dancing and theatre.

Ms CORCORAN—So there is nothing in that line of thought that needs to go into our report as a recommendation?

Dr Asche—I do not think so.

Mrs Barrand—Nothing outstanding, but just to encourage them to continue along these lines.

Dr Asche—You do not need to play bingo.

Mrs Barrand—But you can if you want to.

Ms Miller—You can if you want to, but there is so much else.

Mr MOSSFIELD—I noticed that in your submission you made a recommendation relating to a medication management program, which I think is certainly something that is needed particularly for older people, who I am sure take medication. Could you expand on your ideas. Would you see volunteers with some sort of medical background?

Ms Miller—They would need training.

Mrs Barrand—Yes.

Ms Miller—We have fleshed that out on page 13 and we have a submission as part of this. We are targeting ethnic and Aboriginal seniors particularly, but all seniors with failing eyesight and particularly with memory loss. They may not reliably remember what to take, the dosage or when to take it. With a trained body of volunteers we could perhaps address that, but they would need training.

Mrs Barrand—And we would need the boxes that are provided—in packs, with the days marked on them.

Ms Miller—We say that the medication management benefits would free up hospital beds, lessen the cost of frail aged care services, lessen the prospect of premature residential placement and, obviously, improve the quality of life for seniors and carers.

Mrs Barrand—Sometimes for seniors it is easier to remember what they did 20 years ago, but they would say ‘Did I take my tablets this morning?’

Ms Miller—I speak from experience: my mother had dreadful problems with medication.

Mrs Barrand—The little boxes that have the days marked on are very good.

CHAIR—Do you think this is more than the average carer currently deals with?

Mrs Barrand—It depends on what you mean. The hypothetical person who is forgetting may not even have a carer coming to do things for her, but it would help if she had a person who came once a week, or even more often than once a week if necessary, and fixed her medications,.

Mr MOSSFIELD—Have you started any pilot programs in that field that the committee might be able to pick up on, or is it just an idea at the moment?

Ms Miller—It is a new idea that has come to us. We will take it further and we will be making application for funding of a pilot program because we believe it is an excellent idea.

Mr MOSSFIELD—What does your organisation do in a practical sense to help the Aboriginal communities? Have you got any particular programs running that your members participate in?

Ms Miller—No. We have to use our contacts in the Territory. Because we have all lived here a very long time and we have an excellent board, we have superb contacts and we use our networks for information. Local government is a superb way to get information about the Territory. There is local government in every community, and you can usually get a candid assessment of situations and what is going on. On 27 February, I and our project officer will leap into a car and drive down the track to Alice, visiting every community within reasonable access of the highway, and then drive back again. That will take us 10 days and that will take our two workers out of the office. Our volunteers will man the office during that time. That will be the first time COTA has done that in quite some time. We will visit probably half-a-dozen Aboriginal communities on the way, as well as all the other centres.

Mr MOSSFIELD—I think that will be very useful to enable you to assess some of the needs of the communities.

Ms Miller—Absolutely.

Ms HALL—I would like a clarification from Mrs Barrant regarding the evidence she was giving about palliative care. Is there no in-home palliative care in Darwin? Is there no more general palliative care in communities outside Darwin? You referred to only two beds being available. My understanding of palliative care is that it is a very broad, wide-ranging service.

Mrs Barrant—Yes. I would have to take on notice the question about what is available throughout Darwin and the Territory. I only know what is available as a question of beds available for people.

Ms HALL—So that was just a narrow concept of palliative care rather than the broader concept of palliative care?

Mrs Barrant—I suppose you could say that, although I think that ultimately palliative care has to provide some place, because you reach the point when it is necessary.

Ms HALL—Maybe the representatives from the Northern Territory government, who I notice are still in the room, may be able to provide the committee with evidence on that. I do not have another question, but I think it is important to put on the record that figures relating to Indigenous health are comparable in remote areas, regional provisional areas and urban areas. There is that same significant difference in the morbidity and mortality rates. I think that is very important to put on the record.

Dr Asche—I just want to add to that. I suppose you are aware that we have only five hospitals.

Ms HALL—Yes.

Dr Asche—The communities do not have facilities for even overnight stay, so in the Top End we have our regional doctors sitting in offices, and the community health person—who may be an Indigenous trained person or a nurse who has been trained in one of the hospitals—rings in and describes the symptoms of the patient. In the Top End we send out the doctor on a plane or we bring in the patient on a plane. We have one company which provides all these planes. In the Centre they have the Flying Doctor Service, which is similar. So to have a palliative care scheme out in a community would be very difficult. You would have to change the culture and have Aborigines understanding about looking after—

Ms HALL—Yesterday we received evidence about palliative care that is provided in Indigenous communities, so I needed it clarified for me. I have already been given information that palliative care is provided in communities, and I have asked the Northern Territory government to provide me with information so that I can clarify whether or not it actually exists.

CHAIR—We are going to have wind it up there. Thank you very much, Ms Miller, Mrs Barrand and Dr Asche. Is it the wish of the committee to accept their submission as evidence? There being no objection, it is so ordered.

[10.23 a.m.]

HALLIDAY, Mr Garry Stephen, Executive Director, Northern Territory Carers Association Inc.

McKELL, Miss Janelle Lisa, Team Leader, Carer Services and Information, Northern Territory Carers Association Inc.

SIMMONS, Mrs Leonie Margaret, Respite Manager, Northern Territory Carers Association Inc.

CHAIR—Welcome. I reiterate that this is a formal session of the federal parliament and that you can be held accountable for what you say. I invite you to make some comments on the capacity in which you appear and then to make an opening statement.

Mr Halliday—We are here representing the NT Carers Association and we are also here as professionals in service delivery to unpaid family carers in the Northern Territory, which, by its very nature, maybe has some different perspectives on the delivery of care. Besides being the executive director of the NT Carers Association, I am a social worker. I have had the experience of being a family carer and, when I was suffering from quite a debilitating illness, a recipient of family care. My colleague Leonie Simmons came to us with a background of working in the aged care industry both as a nurse and a manager, and she has also worked in setting up and operating aged care facilities in Indigenous communities. My colleague Janelle McKell is also a social worker, and she is the manager of the Northern Territory Commonwealth Carer Resource Centre. Janelle has about five years experience working with carers both in support delivery and in the education and training of service providers.

We are not academics or demographers, and we are not policy writers. Therefore, our short presentation takes for granted the facts and figures that have already been given to you. We refer you particularly to the written submission from Carers Australia, which was presented in about October 2003. Our plea to this committee is that in your deliberations you take the impact of provision of unpaid family care on care providers seriously, and that you back that up with policies which support unpaid carers. We bring to our submission the perspective of family members who provide care for people who are frail, aged, chronically ill or disabled. When you look at it you see that this is quite different from the medical model, which many bring to the subject. The medical model is that the person with the frail or aged difficulty or disability is the patient and all efforts are focused on them.

Family carers provide about 75 per cent of the care which is provided in our community. However, unfortunately the situation is that they are often treated as supplicants to do the bidding of the health professionals. When they do raise issues they are very often dismissed as nuisances. To put things into perspective, in the Northern Territory, there are—according to the 1998 figures, which are now a little bit dated—an estimated 24,500 carers. Of these, about 5,000 are primary carers—that is, people who provide most of the care in a situation. These figures are certainly under-representative of the true situation. From our experience—and the NT Carers Association provides significant services to Indigenous communities—we know that, given the

high level of morbidity in those communities, the percentage of the populations in those communities who are providing care is significantly higher than the one in 13, which is the national figure that is used.

We estimate, and we can only estimate because there are no figures available, that there are 8,000 to 10,000 carers in Indigenous communities in the Northern Territory. Those carers have the same issues that all carers have, and I will come to all carers in a moment. But the problems of carers in Indigenous communities are intensified by the lenses of isolation, poverty, languages—and there are 28 languages spoken in the Northern Territory—lack of services, family breakdown and cultural confusion, which is apparent in many of the communities at the moment.

As an organisation, we are committed to the recognition of the role played by unpaid family carers and the provision of the highest quality of service to these carers and the people they care for. To achieve that aim, we provide direct service delivery in the way of respite, counselling, carer support, emotional support, education and advocacy—most of which is, in the Northern Territory, funded through the Department of Health and Ageing. We also are involved in community development programs on Indigenous communities particularly and with the development of support groups in the wider community. We also think we could have some input into the development of public policy. We look forward to a time when unpaid family carers and associated individuals and groups are recognised as an important element of our community and have access to timeless, seamless and appropriate support services which are delivered in a respectful manner. We suggest that this may not be the case at the moment.

There is no doubt, with the ageing of the population—and you do have the figures—that there is going to be a greater need for unpaid family carers. I keep using the term ‘unpaid family carers’ because the generic term ‘carers’ is fine, except that it has been confused and hijacked a little over recent time, in that people who are being paid to provide care through HACC services and so forth are also referred to as carers, and we want to be very specific that here we are talking about the family members and the friends who provide care and are not being paid for it. Some would say that the provision of care to a family member is what is expected of a family member. With respect, we believe that this 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 long periods without profound impacts on care providers. These include negative impacts on physical and mental health, family relationships and life possibilities and lead too often in the Australian situation to poverty.

It is these carers who are our daily work, and we are very happy to talk to you about some of the issues that arise with our clients. The challenge for the future is to recognise the role of those who choose to be carers as an important part of the health system. We believe that this requires the adoption of a formal carer policy by all levels of government, providing carers with rights and identifying the community’s and the government’s responsibilities to provide adequate support for carers. The rights of carers should include 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

negative implications of making that decision. This means that accessible and affordable alternatives must be available and that when the decision to provide care is taken the services promised are available in a timely manner. 'Welcome to the waiting list,' is not acceptable and, unfortunately, that is the experience of many of our clients today. The challenge is to make that not be their experience in the future.

Current policy—and, unfortunately, what seems to be future policy if, as I believe, we can use the current discussion going on about community care within the department of ageing—seems to be based upon the belief that there will be an endless supply of family carers. We suggest that this is not the case. The increase in the prevalence of single parent families, the fact that women are delaying starting families, the economic imperative for many families to have two incomes to pay high mortgage rates et cetera, combined with a breakdown of cultural imperatives to provide care for family members, support our apprehension about the availability of an adequate pool of carers in the future.

In the Northern Territory context, the special needs of ageing people in Indigenous communities need to be addressed. Currently there are high birth rates in Indigenous communities. However, the cultural breakdown involving alcohol and other substance abuse combined with poverty and high morbidity is a serious concern. If the situation remains as it is, early onset of ageing related illnesses will continue and the supply of able family carers will be further depleted.

In addition to the above issues, we experience difficulties on a daily basis with the situation at the moment. We would pray that in your deliberations attention is given to overcoming some of these issues. Very briefly—when good policy is put into place, such as the EACH scheme, let us not then complicate it so much with exclusions, inclusions, bits and pieces and rules and regulations that it is made almost unworkable as far as carers are concerned. Carers need to be kept in the work force. We are being told that people will need to work longer. That is fine; however, if they are then placed in the situation of providing care, as the situation exists at the moment with means testing so forth, people are being forced out of the work force to maintain health cards for their spouses. The other alternative, of course, is to divorce and break up the family. Using that concept, they can maintain health cards. Unfortunately, people are being forced to make that decision.

Carers need respite—not the promise of respite or the idea that there is a phone number that they can call to be told, 'Yes, you might be able to get emergency respite in four or five months time, if we have got enough money,' but respite when they need it. This, particularly, is an emergency situation. It is the unavailability of respite that causes people to want to give up caring.

Our carers are too important to be spending time mucked around by Centrelink. Something has to be done about the system that currently exists. They should not have to be stuck in lines waiting and hoping that they will luck out and find somebody behind the counter who knows what is going on or have to sit on a telephone for up to an hour—in some cases over an hour—listening to *Greensleeves* and then be told the wrong information. It is not good enough and something has to be done about it. HACC services in place to keep people in the community are fine, but if you are going to keep people in the community, provide adequate funding and make sure that the people who provide the services through HACC are adequately trained and

adequately paid. Our carers need a health system that works, not one which is based upon waiting lists, which is unfortunately the situation now.

An ageing community means that we have an increasing number of ageing carers. These people need to be assured that there is something in place to provide care if they happen to die before the person they care for—and this is sometimes the case. Unfortunately, that is not the case at the moment in many instances. Carers should not be forced to continue to care and be in untenable situations simply because there is no alternative.

Finally, we urge you not fall into the trap of considering family carers as an unlimited and free work force. They are there and they are happy to provide care to their family members, but they need support. They should not be carrying the costs of providing that support. Caring should be a positive experience for everybody involved: the care recipient and the care provider. Unfortunately, in many instances at the moment, it is not. The challenge is to overcome some of those problems to make it such an experience in the future.

CHAIR—Thank you. We are talking about people who are looking after their own parents, more or less—not always, but basically.

Mr Halliday—The figures indicate that people are looking after their own parents, but a significant number of people look after their spouse.

CHAIR—I just wanted to clear that up. We are talking about unpaid people and we are talking about the general population. So how do most of them know about you?

Mr Halliday—About the NT Carers Association?

CHAIR—Yes.

Mr Halliday—There is an advertising type program that operates at a low level all the time. We make a lot of effort to get out and be seen, to network with other organisations, get referrals through other organisations, go to communities, talk—

CHAIR—Mostly it would be through referrals from other organisations?

Mr Halliday—Yes, I would say so.

CHAIR—Right. You were talking earlier about carers in remote communities and specifically Aboriginal communities. Were you saying that there is a higher proportion of carers looking after their own amongst the Aboriginal population than there is in the rest of the community, or were you simply making the point that they are probably doing it in less auspicious circumstances?

Mr Halliday—Both.

CHAIR—So there is a higher proportion?

Mr Halliday—The figures indicate that in Aboriginal or Indigenous communities in the Top End of the Northern Territory diabetes, for example, is three times more prevalent than it is anywhere else. On that basis one would suggest that—

Mrs Simmons—Kidney disease as well is huge in the Northern Territory.

Mr Halliday—On the basis that there are so many more people suffering from disabilities of various types in the communities and the fact that these people are being provided with care in the communities, it would stand to reason that there are more carers. We would suggest that that figure could be as high as three times the proportionate number of carers in the wider community.

Mr MOSSFIELD—One thing that strikes me is that we would have to be looking at a somewhat different program relating to carers for Aboriginal communities, because of the different cultures, as distinct to one relating to the white community. So I think they would each have to be looked at somewhat separately. But just give me an example: it is quite possible now that people in white society have strokes at a fairly young age and sometimes it means that the other partner has to look after that person. What sort of respite would you be suggesting for, say, a wife who is looking after a husband who has had a stroke?

Mrs Simmons—Is this in Indigenous communities or—

Mr MOSSFIELD—No, just, say, in white society, as a starting point.

Mrs Simmons—There are a few different types of respite care. If possible the person can have respite by having care workers coming into the home, to give them some relief. We have eight respite nursing home beds that we can put people into through the year on two-week or three-week blocks. That means the care recipient will go into the nursing home for two or three weeks at a time.

Mr MOSSFIELD—I see, so the care recipient would go in?

Mrs Simmons—Yes. Sometimes respite care might take the form of actually taking the carer out of the home and replacing them with a family member from interstate. There are many and varied forms of assistance, and we give assistance in any shape or form that we can to stop the carer burnout. But those are basically the three types of ways: replacing the care, assisting them in home, or putting them into nursing home care.

Miss McKell—If I could just emphasise with that that the respite centre that Leonie is referring to only provides short-term and emergency support services to carers. Obviously in the communities there are other supports—such as the HACC programs—that provide ongoing supports to those same clients, but those would not exclude them from being able to access additional support services through the respite centre if necessary.

Mr MOSSFIELD—So what experience have you had with the Aboriginal community in providing respite care for carers.

Mrs Simmons—We have a few programs that we run for the Indigenous community. We do the same kind of care. We offer to bring people into Darwin. I have been involved in setting up respite centres, and the respite centre I set up in Port Keats works effectively. It has overnight stay. It caters for eight people at a time. It is an emergency respite centre. In other words, it is not purpose built. That copes well and that has prevented approximately three-quarters—at least—of the people that used to come in from Port Keats for respite care in Juninga Centre from coming in.

Other forms of respite that we do on community are as follows. If there are health care workers that can be paid to do extra work in the homes occasionally, especially in cases of palliative care, we will work with palliative care in providing some services during that time. We have a service that has been set up over the last few years called the Responsive Respite Program, which involves two Toyota troop carriers with a trailer and camping gear going to communities for approximately one month at a time. We now have a worker to manage that program. During that time we will work with either the women's centres or the aged care centres to take carers, or their families, out on camping or fishing trips, to ceremonies, to back-to-country campouts—whatever way we can. That is the most popular form of respite we can give at the moment. We have had tremendous feedback from that, and we keep getting asked for more and more. We now have two troop carriers, whereas we started the year with one. We now have a person to run that program, where previously it was part of my job.

It is a very popular service and one that I would like to continue. The one disadvantage of that service is that it is not always that great during the wet season because you cannot use it to go to community. During that time it can be used to support the assisting HACC services and aged care services on community.

Miss McKell—One of the biggest advantages of that particular program is simply that we can get so much community involvement. You actually go out and talk to the community and find out how they can use that particular program, so they have a lot of ownership. That is one of the key reasons why it works—because they can actually make it appropriate to their own needs at that time.

Mrs Simmons—One of the things that we have discovered in running this program is the huge number of carers. Each time we go out we find more and more carers as they become aware of who we are. It is a tremendous promotion of NT Carers. It gives education and information of what is available to them right across the board as well as what we can give them. They are just coming out of the woodwork. We call them 'hidden carers', and every time we go to community for a month we come back with 14 to 20 more carers on our books.

Ms CORCORAN—I understand from what you have said that you are mainly speaking about full-time carers. But I assume that there are many people, who are in the work force perhaps, who are providing part-time care. So they run a day job and then they come home and have to care for their care recipient.

Mr Halliday—If I gave that impression, I meant that there are some people who are full-time carers. We talk about 'primary carers', many of whom do try to hold down jobs.

Ms CORCORAN—So when you say ‘unpaid carers’, that does not necessarily relate to an individual who does not have any source of income; it is that they are not paid for the care that they give.

Mrs Simmons—As long as they are doing 20 hours a week they are considered a client of ours. On our database we might have two or three people put down as carers for the one person. In Indigenous communities, especially, you will have two or three people doing the caring, but there will be primary carers and then others involved in the caring role.

Ms CORCORAN—On the radio about six months ago I heard of a program they are starting in England. We are used to the concept of child care being provided at workplaces; they are starting a concept of parent care at workplaces. I wondered if I could get a reaction to that.

Mrs Simmons—That would be fantastic.

Mr Halliday—We would love a situation like that. As it stands, without that sort of service available in Darwin, many people are forced out of the work force to provide care. As the community ages, there is obviously going to be a greater demand for services, and day care for people who are frail aged and with disabilities—and you are interested today mainly in the frail aged—would be a development which would be advantageous and, I think, almost inevitable as time goes by.

Miss McKell—One of the biggest issues that we have in Darwin at the moment is any sort of suitable day care, whether that be located in offices or anywhere else. As was stated aptly before, increasingly we are finding that there are a lot of options for older people who are able to get around and look after themselves. If that person simply needs a hand to go to the toilet, those options stop instantly. Unless they can afford to have a full-time support worker with them to access the toilet, they cannot go to the bingo or any of those different social options that are available. If there were simple day care options that did not necessarily have complex care cases in them but had the option of helping with a meal, or just helping someone to the toilet, it would vastly improve the services in Darwin.

Mrs Simmons—And would relieve our respite funds to an incredible degree.

Ms HALL—Do you provide any training for carers, or is there any training available in Darwin for carers?

Miss McKell—There is currently a very in-depth program being developed on a national level by Carers Australia—I think it is of about eight weeks—for people who are identified as new carers. Beyond that at the moment there are little bits and pieces that happen around the place, but there is nothing formalised. We basically provide an in-depth assessment when we go out to a new client. It is more on a one-on-one basis rather than on a training basis at this stage.

Mrs Simmons—We are developing a training program at the moment for Indigenous carers—that is, with the ability to do it in language. We are in the process of applying for funds for a special person to provide full-time training for carers.

Ms HALL—That sounds very good. What sorts of support networks or services are available for carers within Darwin and the NT generally?

Mr Halliday—For carers?

Ms HALL—Yes. Do your organisations provide support?

Mr Halliday—Yes. We provide emotional support in that we have people who answer telephones and can talk to people in situations. We have support groups for carers. There are some general carer support groups and we also have support groups that are providing care for particular issues like brain injury, autism and that sort of thing. We are able to provide counselling for carers. There is a respite service, which we have already discussed. There is within Darwin reasonably significant networking between organisations, such as the Autism Association, COTA and Carers Australia. There is a reasonable amount of cross-referral and so forth that goes on.

Miss McKell—As far as the services that are available for people in the community go, that really does depend on what the particular issue is. For example, in the field of dementia at the moment there are considerably more services than there are for frail aged with other issues—as I mentioned before about the day care centres. At the moment we do have a dementia day care unit. We have a dementia support service and the Alzheimer's Association and then we have all of the additional services, such as HACC and the NT Carers Association, that can provide additional support. But if you look again at that basic issue of needing help to go to the toilet you see it is a whole different field altogether and the services may not be there. So it really does depend on the situation as to what is available to people.

Ms HALL—If you were to recommend to the committee the three things that are most important for carers, the strategies that need to be put in place, what would they be?

Mr Halliday—We can vote on this.

Ms HALL—No, you can each have a go. We will take a majority.

Mr Halliday—I would suggest that, firstly, adequate respite opportunities—that is, adequate breaks from the caring situation—are vital. Secondly, income support is important—that is, that people have an adequate income to be able to provide the care and do not go into poverty to provide care. Thirdly, recognition is an issue which many carers raise with us. They get really angry when they go and talk to doctors and so forth and are ignored. That is an ongoing problem expressed by many.

Mrs Simmons—Every time we have a conference or get-together, carers say that the systems in general do not recognise carers. Right across the board that is the common complaint—that the issue is with the person that they are caring for and they are not included. They really have to fight hard to get that recognition.

Miss McKell—I have two shopping lists.

Ms HALL—I am interested in both; or the committee is.

Miss McKell—With regard to carers specifically, service availability and choice of services are critical. Where we actually have some services at the moment there is no choice so you have to get what you are given and if you are not happy it is too bad. Financial support is certainly a big issue. We recently opened up in our office a no-interest loan scheme, which is very popular. We were talking about waiting lists: we have waiting lists coming out of our ears of people wanting to borrow \$1,000, just to in some cases buy the contents of their house back from the hock shop. It is about being included in the medical model somehow. That is about finding a way for GPs to acknowledge that the carers actually are a key component in that and looking at it more holistically so there is more care inclusion there. That is my carer list. If you want the other one, I can go into that afterwards.

Ms HALL—Yes, of course. Give me the other one.

Miss McKell—I just wanted to point out that in Darwin, with ageing specifically, we have some particular issues with regard to gender imbalance. There are more males than females in Darwin, which I understand is the reverse of everywhere else in Australia. That is going to give us some really difficult issues to overcome in the next few years, because carers are predominantly females. We are going to have a lot of single men out there who are isolated and not able to access support and who do not know where to go to get it. That is it quite clear at the moment in the gender imbalance in the palliative care volunteer program which we have recently started. It is predominantly men needing support because they do not have carers and they do not have anyone to talk to. That gender imbalance is going to be a huge issue for the Territory.

I also wanted to point out something about day care options, which we talked about. Low-care hostel options are another thing that are seriously lacking in the Northern Territory—by that, I mean the retirement village set-up. I believe we only have the masonic lodges in Darwin. If you just want a low level of support—a button that you can push if you fall over—there are not really a lot of options there. That is something that needs to be explored.

Something else that needs to be taken into consideration when looking at any issues from the Northern Territory is simply the fact that there is family isolation, as Garry was pointing out before with the carer issues. It is not necessarily the case now in Darwin that an undefinable pool of carers exists; and, if it does, that is certainly going to change, because families are fragmenting. People in Darwin do not have that family support. The carer issues that are going to come up in the next few years are going to be much greater. That is my belief, in any case.

CHAIR—Thank you very much.

Mr HARTSUYKER—Those two lists pretty much answered my questions.

CHAIR—Thank you very much for appearing before us. Is it the wish of the committee that the submission from the Northern Territory Carers Association be accepted? There being no objection, it is so ordered.

Proceedings suspended from 10.58 a.m. to 11.13 a.m.

JEFFERY, Mrs Rosemary, Director of Nursing, Terrace Gardens, Uniting Church Frontier Services

PHILLIPS, Mrs Caroline, Director of Nursing, Juninga Centre; and Manager, Tracy Aged Care, Uniting Church Frontier Services

RATAJEC, Mrs Judy, Coordinator, Territory Older Persons Support Services, Uniting Church Frontier Services

CHAIR—Welcome. I remind you all that this is a formal hearing of parliament and you are asked to consider that in your answers. Do you have any comments to make on the capacity in which you appear?

Mrs Ratajec—Territory Older Persons Support Services is a psychogeriatric liaison service that covers all of the NT.

CHAIR—Thank you. Would you like to make an opening statement?

Mrs Ratajec—We would like to read a statement that our regional manager has prepared, and we will speak to that as we go. It starts with a brief background of Frontier Services. Formerly the Australian Inland Mission, Frontier Services was established in 1912 by Reverend John Flynn, the legendary ‘Flynn of the Inland’. He had a vision of bringing health care and other services to isolated people in inland Australia and establishing a ‘mantle of safety’ so they could live in peace and security amidst the hardships of the outback life. Flynn’s vision for outback people continues today through Frontier Services. It is still the welcome visitor, the friend, the counsellor and the advocate for bush people. With more than 400 staff in over 65 programs, our operations cover 7.5 million square kilometres—about 85 per cent of the continent. Every year, Frontier Services provides care, support and friendship to tens of thousands of people in outback Australia.

Today, for those living in the outback, the frailty of age or the disadvantage of disability is often made worse by distance from services and family. Frontier Services provides a range of home and community care services in Western Australia, western Queensland, South Australia and the NT, as well as community care packages in Western Australia and the Northern Territory. Our staff make hundreds of visits to the elderly and to people with disabilities, ensuring these people can live for as long as possible in their own homes.

In the NT, Frontier Services is the largest provider of residential aged care, with Terrace Gardens, which is at Palmerston, Darwin; Old Timers in Alice Springs; Flynn Lodge in Alice Springs; Pulkapulka Kari in Tennant Creek; Rocky Ridge in Katherine; Tracy Aged Care in Darwin; and the Juninga Centre, which Frontier Services manages in partnership with the Gwalwa Daraniki Association, which is also in Darwin. We also provide a number of respite, community based care and referral services: Commonwealth Carelink, Territory Older Persons Support Services, Respite Options for Senior Territorians, Carer Respite Centre, Fred McKay Day Therapy Centre, HACC Transport, and Frontier Services Community Care Darwin and

Alice Springs, community aged care packages. As a leader in the field, Frontier Services is often called in to provide expert advice and support to other service providers. Thank you.

Mrs Jeffery—I am going to address some of the current issues that we have. I would just like to say that ageing for the Northern Territory in the next 40 years will include me, so I would like to think that we are going to have it pretty right! I do not think we have got it right currently, so we need to do a bit of work. Access to services is an issue that we see. In rural and remote areas of the Northern Territory, access to health professionals as well as volunteers and suitably qualified staff is difficult. Life in Darwin itself is not so difficult, but certainly in Tennant Creek and Katherine and those places it is very difficult to access the health professionals that you need to be able to care for people in residential aged care.

Regarding residential care funding, I guess is not anything new to anybody, but we cannot manage on what we get. We manage better in the urban areas, but the remote areas are just ridiculous in the amount of money that Frontier Services needs to provide to top up the funding. If we leave, nobody will do it. That is the way it is. That is the reality. As we said earlier in the piece, our objective is to provide things to people in the bush who need them. That is why we stay.

We believe there is a new class of poverty in residential aged care. Even though they pay 85 per cent of their pension, the remaining money is not enough to survive on for most people. They have to pay for their medication on top of that, and usually that soaks up the money so they are left with nothing. If they smoke, they are in severe difficulties. Many people have said to me, 'But they shouldn't smoke.' Well, if I got put in a residential aged care facility and was told to stop smoking, I think I would be very upset. They are not the best places to live, but it is necessary for some people to live in those facilities, and they are not going to give up smoking when they get there. As much as we argue against it in the health world, the reality on the ground is that they are not giving up smoking. I subsidise one of our residents \$60 a week for her cigarettes because she cannot afford them. That sort of thing goes on all the time in aged care. Many of our residents are smokers or drinkers and they should be able to have a drink and a smoke in their old age. This is a real issue. They really are poor people. There is a bit of a discrepancy too, in that many Aboriginal people get their medication subsidised and some do not. That is an inequity that exists among the Aboriginal people.

We all suffer from the problem of distance in the Northern Territory. We pay extra for freight, we pay extra for everything and it is difficult to get hold of things at times. We spend a lot of money on recruitment and getting staff into Alice Springs. We have to pay airfares, accommodation, meals and all sorts of things to deliver the same care, the same amount of work, as somebody who lives locally. It is very unsettling and unfair for people.

Culture is a big thing. There are eight or 10 Aboriginal people living in my particular facility. I think you would find from statistics that, once they reside in a residential aged care facility, their life expectancy increases because the nutrition is good and the health care is good. All those aspects are good but I do not believe we deliver the cultural aspects to them that they should get, although we do our very best. We bend over backwards to have culturally appropriate functions, food and all that sort of stuff, but it is really a bandaid. It is not the same as living in their own community, but we do our best.

Finding staff to be culturally related to our clients is difficult. You have a lot of complications, within the culture, of certain people not caring for certain people, men not being washed by women and all that sort of stuff, so it gets very complex. There are still not the numbers of Aboriginal people delivering care in high-care facilities or low-care facilities. Frontier Services loses up to \$300,000 a year to support its more remote facilities. From a personal perspective, I run a 56-bed facility in Darwin and I am having extreme difficulties making ends meet. In fact, if anything wears me out and makes me older before my time, it will be trying to make ends meet in an aged care facility.

We have a lack of geriatric specific beds and services. We have a very high percentage of dementia—we have a lot of alcohol related dementia in the Northern Territory. We have a psychogeriatrician in town at the moment, living in Katherine, but that has only just recently occurred. We have had to import somebody all the time. That does not give us continuity of care, continuity of diagnosis and things like that. It really has been a difficult time for the Northern Territory, not having a gerontologist to help us cope with the difficult people we have. I do believe we have some very disabled and very demented people who have huge behavioural problems that we pride ourselves on being able to manage, but we often do not have the expertise to support us.

Specialist training: GPs certainly need more training in gerontology aspects, but we have difficulty finding GPs who will come to nursing homes. They just do not want to come. They do not get paid enough. Unless they look after a resident in the nursing home, it is not worth it. We cannot run nursing homes like that—people have to have choice. So we have extreme difficulties in finding GPs. We are great believers in Community Aged Care Packages. We think that each program is a wonderful way to go, but they still have to be well supported. I think they have to be broader to be able to deliver care that is very flexible.

As an example of a Community Aged Care Package, in Darwin, we had a gentleman who lived on the pipeline at Mitchell Creek—that was his address. We had to go into the bush and find him to deliver meals to him. The normal package would be to go down and shower him and so on, but we made it flexible enough to just deliver his meals to him. That was all we did for him. We could bring him to a shower at the nursing home once a week. That is how flexible they have to be. Everything has to be so flexible that you can tailor it to suit the individual, so he can maintain his life on the pipeline at Mitchell Creek, which is a pretty amazing place to live.

Multipurpose schemes have worked quite well in lots of areas but, because of the spread of our population, it is not the way to go all the time. We have too many people spread too far and wide to put it all under one umbrella; it is very difficult. Caroline is now going to tell us what we need for the future, but that is what is happening at the moment.

Mrs Phillips—Some of the future issues we have identified include the fact that, because of the increasing number of people that are being cared for in their homes, the people coming into the facilities have much higher care needs by the time they come to us. Yet, at the same time, we are downgrading the skills mix of staff and services due to the lack of funding. It should be the other way around. We are getting very sick people in our homes. The other impact, particularly in Darwin at the moment, is that it has cut our waiting lists. Since the new facility opened last year it has soaked up our waiting list. At the Juninga Centre, which is the Indigenous facility that I run, we struggle to fill our beds, because there are lots of schemes doing Community Aged

Care Packages in communities. It is much more appropriate for Indigenous people to stay in their communities, but it is having an impact on maintaining our beds in Darwin.

At times, we increase our respite beds to help support these services on communities. Where I cannot fill a permanent bed, we increase the number of respite people that we have in. At times, we have had up to six respite residents in a 26-bed facility. There is also a need, particularly in Darwin, for supported accommodation. In running Tracy Aged Care I have found there are a lot of people on the waiting lists who come under category 8, where you get no funding. Again, as has been brought up previously, there are a lot of single men who have no family and cannot stay in places on their own. They do not need a lot of care, but they need their meals cooked for them and their laundry done. That is a big need that we do not have in Darwin. There are a lot of people in hospital waiting for a bed because they just need supported accommodation. With a Community Aged Care Package, that would work.

We will be seeing a bigger increase in dementia related disorders up here. There will be a need for much more specialised services, especially in the community, so that people can be managed at home. Dementia has been identified as an epidemic that will impact greatly on the economy. Increases are expected in the Territory in particular, due to head injury, diabetes, vascular disease, early ageing et cetera. Also there is the additional unknown impact of substance abuse, which is pretty rife up here, and the increased lifespan of those clients currently cared for in the disability sector.

In terms of cultural diversity, an increase is projected in the NT aged population as more people now choose to retire here, which you have heard previously, especially people from non-English-speaking backgrounds. The lack of qualified staff is going to get worse. The Territory in particular has seen the impact of having fewer registered nurses. Recruiting is very difficult. You can put an ad in the paper and get no response. Running facilities that require registered nurses 24-hours a day has brought with it some pretty difficult times. I ran the nursing home in Katherine for 10 years. Many times, I had to do the night duty myself because there was no-one else. For managers, there is a big burnout factor as well.

Also, as Rosemary mentioned, there is the GP situation, which I think is only going to get worse. We have three residents in the facility that do not have a doctor willing to care for them. It is crazy. They would have to go to the hospital for any care needs and for any after-hours needs. In the Territory in particular, private doctors are not on-call, so for any after-hours needs they had to get in an ambulance and go to hospital. For that we get a lot of anger from the hospital. The hospital treats us pretty badly if we put someone in an ambulance and send them up there. We know that it is only for something minor. We know they just need to see a doctor. However, we have no-one else to access. But the hospital will ring back and say, 'What are you doing?' and we say, 'We just need a doctor.' So there are a lot of issues with the public health sector as well.

There is a lot of misunderstanding, as the lack of funding gets bigger in every area. The hospital gets very anxious to get people out as quickly as possible. We have a lot of issues, particularly in low-care facilities, where people are sent out and we suddenly realise we are not going to be able to manage them. They are big things that will only increase, I believe. In relation to the not-for-profit sector, there has been an increased expectation that it will

supplement the viability of remote, rural and regional areas of Australia, and this is not sustainable.

CHAIR—Thank you very much. Mrs Phillips, when you were talking about the fact that it is harder now to fill the places, was that in an Indigenous community?

Mrs Phillips—It is very much across the board in the Territory, particularly in Indigenous communities. I know Juninga has gone six weeks with two empty beds.

CHAIR—Is that because of the aged care packages?

Mrs Phillips—Yes, it has had a big impact because more and more people are staying in their communities and not coming to Darwin for care.

Mrs Jeffery—As Northern Territory Carers said earlier, because they provide a lot of respite and our people are not accessing residential aged care as much as they used to, it has had an impact. We actually think we are over-bedded in the Northern Territory as far as residential care goes. It has made it tough for all of us.

CHAIR—In your facility here in Darwin, are most of your people coming in as low care or high care?

Mrs Jeffery—My facility is for high care, so I only take high care.

CHAIR—So you do not have any bonds?

Mrs Jeffery—No.

CHAIR—Do you, Mrs Ratajec?

Mrs Ratajec—No, I do not. I am not in residential care.

Mrs Phillips—Tracy Aged Care is a low-care facility and has bonds but not many.

Mrs Jeffery—Tracy Aged Care used to have high and low care, but it found that it was not sustainable as far as registered nurses go to maintain it. It was not possible to do ageing in place, so it went back to low care. I do not think our facilities are big enough to maintain high and low. Some of the other facilities are looking at it and doing it, but you would need to be a reasonable size to maintain the required level of staffing.

CHAIR—You probably said this and I missed it, but are all your frontier services in Darwin?

Mrs Jeffery—No. They go right down the track to Alice Springs.

CHAIR—Where are they?

Mrs Jeffery—Alice Springs, Katherine, Tennant Creek and Darwin.

Ms CORCORAN—You used the term ‘over-bedded’ before. This happens nowhere else in Australia, let you tell you.

Mrs Jeffery—Absolutely. People get shocked when I mention that at conferences. They cannot believe it.

Ms CORCORAN—That is right. I am assuming that relates only to high-care beds?

Mrs Phillips—No.

Ms CORCORAN—Is there an oversupply of low-care beds?

Mrs Phillips—I have empty beds at Tracy Aged Care that I am unable to fill at the moment.

Mrs Jeffery—Of course, we are not going to take eights out of the hospital because it is not viable for us. The hospital and the health department probably think people in hospital are waiting to go into nursing homes—high or low—but they are not. We cannot take them. We cannot manage them. Supported accommodation is required for those people. The other day I had a male high-care bed and there was one person on the list.

Ms CORCORAN—Does this mean that there is a movement for all sorts of different reasons towards the need for more respite and day care than perhaps residential care because of the nature of the communities you are dealing with and because of the situation?

Mrs Phillips—Yes, I think so. We said that maybe at Juninga we need to focus more on respite care for people who are coming in from communities and who are being cared for with a package. But I am finding that I am really struggling to keep my respite beds full as well, because the communities are running more respite. Various communities are now opening respite houses, so they tend to do their own respite in communities. We do tend to get some high-care patients, but I have empty respite beds quite regularly.

Mrs Jeffery—Of course, this is Darwin we are talking about. The other facilities in Katherine, Tennant Creek and Alice Springs have not got as many beds, so it is different for them.

Ms CORCORAN—Yes. We heard a different story in Alice Springs yesterday, particularly with regard to respite. Forgive my ignorance, is respite confined to fixed blocks? Are you able to make decisions about offering three or four days?

Mrs Phillips—Certainly. We do short-term respite; we do anything—whatever. We are pretty flexible with what is needed. One of the things with Indigenous respite in particular is that you tend to have a booking system that says, ‘You’re booked in for March, and you’re booked in for June,’ which does not actually work. Often if there is a death in the family and everyone wants to go and do sorry business the older person really needs to come in then. So we need more of that emergency or immediate respite. I have certainly had phone calls from communities saying, ‘Can dad come in tomorrow?’ And often we have managed to try and help where we can. We had one Christmas where four people came in from one community because everyone went on holidays and forgot to tell everyone else that they were going on holidays. Suddenly we got a phone call saying, ‘Can we fly these four people in?’ And it was a case of saying: ‘Yes, okay.’ So

we are very flexible. Particularly in Indigenous care you need a lot more flexibility. You need the flexibility to be able to increase your bed numbers as necessary, but also to be able to lower them when that is more appropriate, without losing money. The financial impact of having empty beds is huge.

Mrs Jeffery—And right across the Indigenous aspect of putting people into residential care, there are huge complications. You can offer a bed to somebody who lives in Woop Woop, and you do not see them for two weeks because it takes them two weeks to get there. So you are in trouble already because you have not filled the bed. Lots of times Aboriginal culture just does not fit into bureaucratic culture, standards and requirements. There are big gaps. We have people in our facility who desperately need to go home, but they cannot. There is no money to get them home. If they smoke—I am back to the issue of smoking—

Ms CORCORAN—Do you mean there is no money to transport them home or no money for care once they get home?

Mrs Phillips—A mixture.

Mrs Jeffery—Both. They are simply stuck where they are.

Mrs Phillips—In relation to the issue of smoking, poverty in nursing homes is huge. We give out cigarettes—one or two an hour—simply so that they will last. You end up with huge behaviours from these residents because you are forever saying, 'You haven't got a smoke.' One of the biggest issues we deal with in Juninga is that of people always wanting a smoke when they do not have one.

Mrs Jeffery—And we always have to get second-hand clothing for them. We have to cry poor to the op shops. The Uniting Church op shops are usually fairly generous. It is sad.

Ms HALL—You said that at Tracy Aged Care you have very few bonds. Is that because a large number of your residents are concessional residents?

Mrs Phillips—Absolutely.

Ms HALL—So how many pay bonds?

Mrs Phillips—I think there are four or five bonds at the moment.

Ms HALL—Out of how many?

Mrs Phillips—Out of 46 residents.

Ms HALL—That says a lot, doesn't it?

Mrs Phillips—And of course at Juninga it is all concessional. There is no-one that pays a bond.

Ms HALL—How effective is the RCS in an area like the Territory? What are the implications of accountability, bureaucracies et cetera?

Mrs Jeffery—It is a pain in the neck.

Mrs Phillips—I dislike what we are doing now with the RCS in that, if a resident has huge behaviours, they score very low on an RCS. If you do a major category D for every behaviour—and if you are doing a D on every behaviour, you have a very, very difficult resident—the point score only adds up to the same as someone who you are showering once a day. It is just a crazy point score. You can shower someone in half an hour and you get 14 points. If you are encouraging them to help themselves, you get the maximum, which is around 14 points. If you add up the maximum points for every behaviour, it only adds up to 13 points. Yet that can be 24 hours a day, it can impact on every other resident in the place and it can mean you have extra staff on. Behaviours are the hardest things to manage in the facilities, yet they do not score at all well on the RCS. So I do not think it is reflected at all well.

Ms HALL—And what about the red tape?

Mrs Jeffery—It is disgusting that they cannot take the word of a registered nurse and that they have to come and do a random check of six clients to see that the documentation matches the RCS word for word. It is an insult to professional registered nurses. We are equipped to do this, but they still have to check on us to make sure that we have it exactly right. If we have not got one word right, we lose a point, our score drops and we lose our money.

Ms HALL—Have you had many residents reclassified?

Mrs Jeffery—Luckily, they do not visit us too often.

Mrs Phillips—We have not been visited for over three years.

Ms HALL—You are lucky.

Mrs Jeffery—We are lucky.

CHAIR—I think you just dobbed yourself in.

Mrs Jeffery—We do not make any waves unless it is to our advantage.

Mrs Phillips—One of the things that has a big impact at Juninga as well is that residents come in from communities and often they have not been seen by the ACAT team, so they have not actually been approved. Because they have waiting lists, the ACAT team do not come straight away, even though you ring them. I have had residents that have gone within five days, and I have not received funding for them, because they never got around to being approved. Respite residents come in without approval, so a lot of the problem is that you are relying on the ACAT team to turn up and approve them after admission. You often have very little information too; you do not even have an ACAT assessment before these people come in. That is a big issue.

Ms HALL—If you could, please expand on that a little bit more for us. You are saying that, whilst there is not a large waiting time for residential care beds, there is a waiting time for residents or people that need aged care packages to be assessed by the ACAT team.

Mrs Phillips—Yes. We find that we have trouble getting the ACAT team to come in. Also, they do not visit communities very often, so they are not doing their assessment until they actually come into the facility. That can often take up to a week after admission.

Ms HALL—What do you think should be done in that area to streamline that and make it work better?

Mrs Jeffery—Either the ACAT team needs to be able to access those communities better or people in those communities need to be able to make approvals for admission or respite. Either the ACAT team needs to be able to be in more places than it is, or local people—like the local doctor or whoever—need to be able to complete an ACAT form for admission.

Ms HALL—That would be a solution to the problem.

Mrs Jeffery—Yes.

Mrs Phillips—We have also had a problem with residents that are going from low care to high care. When you refer them to the ACAT team to reassess them for high care there is often a long wait. That has been a real problem in the past.

Ms HALL—We have received evidence in a number of places that getting GPs to visit nursing homes is a problem. Do you have any solutions or recommendations to address this? Do you think that there is anything that we could recommend as a committee to address this?

Mrs Phillips—I guess the doctors' biggest complaint is the lack of money, because it is just bulk-billed. That is their main complaint. Also, the doctors are very busy. Fitting in coming to an aged care facility often means they are visiting at eight o'clock at night. We get faxes from one doctor we have who does look after a lot of our residents that he has sent at two o'clock in the morning. So we might be having a big whinge about him not coming, and then we look at his fax. I think there is an overload for the doctors as well.

Mrs Jeffery—There are some pilot schemes being conducted in Melbourne, I believe, with local doctors making a group arrangement that one of them is on call all the time after hours. That minimises the hospital visits. They all take turns, share it and make themselves available to nursing homes on a rotating roster and things like that, which does reduce the hospital admissions. They can come and see the person and decide whether they need to be admitted or not. I have read of a few pilot projects going on in Victoria on those sorts of things. That to us would be an answer. If we got enough GPs on board who would commit themselves to aged care facilities and say, 'We are coming on such and such a day,' and, 'Such and such is available after hours,' it would be wonderful.

Mr HARTSUYKER—You talked about being over bedded, which I have to say is quite a surprise to me. We had an earlier witness talking about the critical need for respite beds. Do you

see a way we can meld that demand that we have been advised of for respite with that over-bedding situation? How can we solve that problem?

Mrs Phillips—One of the ways would be these emergency respite beds. We would actually have beds available that are already funded so that we are not desperately trying to keep them booked ahead of time. That would make a big difference. There was a pilot scheme run several years ago where NT Carers funded respite beds so that it did not matter whether they were empty or full—they continued the funding for them. That worked really well.

Mrs Jeffery—As a facility provider, I have two emergency respite beds which would be full about 90 per cent of the time. I am reluctant to put many more in, because it is very disruptive to the rest of the clients unless you have a separate house. I have cluster housing, which would probably work okay. But you would need a designated area because Joe Blow who has lived there for 20 years has all of a sudden not got his seat at his table, because of the respite person. That sort of stuff goes on. It is fairly disruptive to the regular clients. But there are ways around those sorts of things.

Mrs Ratajec—I think there is a need for psychogeriatric beds as well. We could utilise the beds for that purpose. As Rosemary said, they have very disruptive types of special needs, so they do need to be in an area that is separate from the normal residential beds.

Mr HARTSUYKER—Do you see the funding mechanism as a major impediment in allowing that to happen?

Mrs Jeffery—In capital, in as far as who is going to build a building for it.

Mrs Phillips—I agree with Judy on the psychogeriatric unit. At Tracy Aged Care, we have a dementia specific unit. When we bring new residents in who have not been fully assessed, because they have come from the community or whatever, it can be huge to manage. We had some coming in over Christmas on respite and their behaviour was quite a major disruption to other people. In fact, their behaviour can be threatening to other residents; there is sometimes some violence involved. If they were in an assessment bed first that was separate to the actual facility, it would make life easier.

CHAIR—Rosemary, do you find you are having trouble filling your beds or only just using them?

Mrs Jeffery—We are just hanging in there. If I had a lot of deaths all of a sudden I would probably be in trouble. There are definitely no males on the list at the moment, so I would have to rearrange a few things.

CHAIR—Are the three homes that the two of you look after all you have in Darwin?

Mrs Jeffery—No. There are two more.

CHAIR—Are they the same?

Mrs Jeffery—I think so. We actually steal patients from each other every now and again.

CHAIR—You would.

Mrs Jeffery—Which is not good for either.

CHAIR—It is certainly the day for honesty, isn't it? Would it not be true for you in your outside Darwin facilities?

Mrs Phillips—It is true at times.

Mrs Jeffery—It is true at times in Katherine, but I think Tennant Creek and Alice Springs always have plenty on their lists.

Mrs Phillips—Katherine also has the Little Sisters of Mercy who look after older Aboriginal people. I have often said that they are not added to the statistics but they take a lot of people off the waiting list that would be there if they were not providing this free service.

Ms CORCORAN—Do you happen to know off the top of your head how many aged care beds there are in Darwin?

Mrs Jeffery—I might have to add that up.

Mrs Phillips—Add it up and let me know. One of the impacts of not having waiting lists is that you have no choice. We cannot just say, 'We will only take category 1s or category 2s.' Often we are taking category 6s or category 7s, just to fill a bed.

Mrs Jeffery—The other thing is the resident mix. Sometimes there is somebody on the list who will not fit in with the clients you have but you have to take them.

CHAIR—Thank you. We have people waiting who are on a tight time frame.

Mr MOSSFIELD—I move that this committee accept this letter from Frontier services.

CHAIR—Thank you very much. If there is anything else we want to ask you, we might do it by letter.

Mrs Jeffery—Thank you. And you are most welcome to visit my facility this afternoon if you have time.

CHAIR—We are visiting Mrs Phillips. Thank you.

[11.50 a.m.]

LOWE, Dr Michael Peter, (Private capacity)

MAHAJANI, Dr Sadhara Arun, Geriatrician, Aged Care Assessment Team

CHAIR—Welcome. We particularly asked for the medical fraternity to be represented here today, and obviously you were both good enough to put your hands up or did not refuse. Thank you very much for that. I must tell you that these are formal proceedings of federal parliament and what you say must be within the bounds of credibility. I guess you understand that. We would appreciate it if you could give us your thoughts.

Dr Mahajani—I am a geriatrician in the community. I have lived in Darwin for 30 years and I have worked as a geriatrician for 18 years, since the Aged Care Assessment Team started.

Dr Lowe—I will give a brief statement first and then Dr Mahajani will. I am a physician at the Royal Darwin Hospital and I am trained as a geriatrician. I do not work here as a geriatrician; I work as a physician. I have not worked as a geriatrician for five years, but I do general medicine and look after a lot of elderly people. I thought I would give you the hospital perspective, which is fascinatingly different from the community perspective. I looked through the data before coming here and—I am sure others have told you this—obviously the Northern Territory is very different. Particularly when you examine the recent Australian Institute of Health and Welfare reports, you will see that in almost every measure the Northern Territory stands out as being different to the southern states. The three factors that I will touch on—which I am sure have been touched on by others—include the distribution of the aged in the Northern Territory, the high number of Indigenous people living here and the remoteness of the communities.

Recapping on the aged population, there are few elderly people in the Northern Territory. Ninety-six per cent of the population is aged under 65, compared to 87 per cent Australia wide and as low as 82 per cent in South Australia, and that is reflected in the hospital population. Until recently we felt that elderly people were very rarely in the hospital, but now they are much more common. The reasons the number is growing in the Northern Territory—and we have heard other speakers address this as well—are as follows. Firstly, the Darwin population has grown older in general; also people are bringing their elderly relatives up to Darwin to bask in the sun in the dry season—and probably because they feel that services are better here. There are quite a lot of elderly people being brought up here by younger relatives, who live with them.

The second thing I will talk about is Indigenous people. As you know, 25 per cent of the NT population characterise themselves as Aboriginal, and in Darwin it is nine per cent. This is part of the reason there is a different age structure here. Only 2.8 per cent of the Aboriginal and Torres Strait Islander population is aged 65 or over, compared to 12.5 per cent of the non-Indigenous population. Altogether about 14½ per cent of the Indigenous population is aged 45 or over. I should note that the figures—and I do not think they have changed from the early 1990s—show that only 45 per cent of Aboriginal men and 54 per cent of Aboriginal women

could expect to live until the age of 65. I am not sure that that has changed very much. Finally, I will talk about the remoteness of the area, which we have already touched upon.

As the life expectancy of Aborigines is markedly shorter than that of other Australians, for the purposes of accessing aged care they are often classified as physiologically old. So the number of aged care places is taken into account by looking at the number of non-Indigenous people aged more than 70 and the number of Indigenous people aged more than 50. This results in some of the statistics seeming a bit strange. For example, if you look at the ratio of residential aged care places for every 1,000 people aged 70 or over, the Northern Territory has the highest level of provision at over 100 places per 1,000 people, compared to, say, 76 in the ACT. But, if you put together the non-Indigenous population over 70 and the Indigenous population over 50, then the Northern Territory ratio is 51, compared to the Australian ratio of about 81. On these sorts of measures, we look like we have less than our fair share of residential aged care places. That is what is so fascinating about the last talk, where they were saying that they do not have enough people for residential aged care places. I would just like to put it on notice that at any time I have people in the hospital under my care waiting for residential aged care places.

Ms HALL—And they would be classified as category 7s or lower?

Dr Lowe—That is the issue; that is what I am not entirely sure of—and Dr Mahajani will be able to tell you that—but there is a combination. It is something to do with their characteristics, which means they are waiting for up to two years—or a year, or something like that—for a bed, whereas at the same time community people are saying that they have no beds. We should note that Indigenous people Australia wide have very high-rated usage of community aged care packages, and that is true in the Northern Territory too. Dr Mahajani will talk a little bit more about that.

Looking through the data, one of the difficulties with the data is that data about diagnoses do not appear in the data about reporting to residential aged care, so I cannot really substantiate all my feelings about this. But I will tell you again, from the hospital perspective, that the difficult problems that we have are not with very old people with Alzheimer's disease et cetera but with middle-aged or younger people with alcoholic brain damage or vascular disease and, because Aboriginal people aged over 50 will go to residential care, they come in as 'elderly' in this sort of categorisation. The Northern Territory has the highest rates of alcohol abuse in Australia and there are high rates of tobacco use, particularly among Aboriginal people. In addition, there are high rates for other vascular diseases such as diabetes and hypertension and there is lots of trauma and lots of other substance abuse. Because of this, we see a lot of young people aged from their thirties up who develop dementia from either alcohol or vascular disease—and this includes non-Indigenous and Indigenous people. Conversely, in the hospital we see very few cases of Alzheimer's disease, whereas in the community they are seeing increasing numbers.

The result is that we have these young people with dementia whom we have great trouble knowing what to do with. Australia wide, the proportion of residents in aged care services aged under 65 is four per cent, compared to a Northern Territory average of 20 per cent. I am sure the people in the communities would tell you that a lot of the problems occur in these young people with alcoholic, trauma related or substance abuse related brain damage. When you put these people into aged care, someone with alcoholic brain damage will live quite a long time, because they are not like a 90-year-old person with Alzheimer's disease, who has a limited life

expectancy. If they stop drinking and live in aged care, they can live for a long time. I notice in the statistics that the Northern Territory has an increased number of people who have been in residential care for a long time—that is, over eight years—compared to down south. Some of this, I think, will be because of the different diagnostic mix we have here.

Finally, just to talk about the future, my impression is that there are greater numbers of elderly non-Indigenous people opting to retire to the Northern Territory. Flicking through the submissions, I see that other people have statistics to back this up. This will cause an increased need for services, which I do not think we in the hospital have yet come to grips with, in that we have not been dealing very much with elderly people and we will have to be dealing with them more. A particular problem is assessment services, which is where Dr Mahajani comes into things. They form the key to moving people from acute services to chronic services and, because of limited staffing et cetera, that key is a little bit rusty at times.

Aboriginal people are not living longer, so the need for some sort of care for those aged 50 and above is likely to continue as it is. The best model of care in remote communities is caring for people in their own homes, of course, but there are some problems with that. Many people in Darwin do not have a residence. We see a lot of people who are 'living in the long grass', as we say. You cannot provide community packages for people if they are homeless. There is, therefore, a need for residential services at an earlier age for these indigent alcoholic people, both black and white, in Darwin.

Other speakers spoke about the large number of single men in Darwin, many of them drinkers, many of them living alone without family support and many of them with families who really do not want to have anything to do with them. This is also a problem with looking after people in the community. Another thing that strikes me is that these young people, these 40-, 50- and 60-year-olds with alcohol related brain damage, must have different needs in a nursing home from those of older people. If we are putting 50-year-old young men with alcoholic brain disease in with terribly frail 95-year-old women with Alzheimer's disease, the needs of the two groups must be completely different. Somewhere like Juninga probably manages this very well, because of the sense of community there, but when these young people are put into other nursing homes I suspect they have different needs—and there are many non-Indigenous people in Darwin with these problems. There is an urgent need to provide more care for them. They fall between disability care, which is, as I understand it, a state issue, and aged care, which is a Commonwealth issue. We have a lot of trouble placing these people.

There are a lot of other things to talk about, of course, but there are legal things that may be more an issue at the state level, including the inadequate NT guardianship laws. I would like to plead that we get some Commonwealth standardisation of these, as they are much better done in other places. Regarding the legal difficulties we have in discharging people back to the long grass, back to their communities, what can we do? If we see that they are incapable of looking after themselves but they have no home, we have to discharge them back, with all the legal problems that happen there. So there are a lot more things to talk about, but I might hand on at the moment.

Dr Mahajani—I have been here for a long time, so I have seen Darwin changing quite a bit. We started working here in 1985. There were five ACATs that started first in 1985, and Darwin was one of them. The reason Darwin was included as one of those five experimental ACATs

was that it was so different. We are changing. We are coming towards the general population of Australia. In that sense, when we started, single men who had come from eastern Europe and had no fixed address predominated. Now it is becoming more a question of older women needing nursing home places. The number of people wanting to be in Darwin has increased now, as Dr Lowe said, because people are getting older here and not wanting to leave—because housing provisions and the changes we need to do with housing and all that are much easier here than elsewhere. Also, younger people are bringing their parents here. That is our big problem, because according to the ratios these people are not counted as being in Darwin, but we still have to provide them with help. Even if there are five people who come every month, that is a big number to cope with in a small population. So those are some of the problems we have to face.

I work in an ACAT and I have always strongly believed that community care in the aged area is very important. The hospital component is also important, but the majority of older people are in the community, so the community care that is offered to the elderly is very important. The workload for ACATs has increased phenomenally because every time the new CACPs or nursing home packages come and every time the number of residential places is increased our work increases. And we have not had any increase in funding. I will give an example of the difference that has taken place over two years. In 2001 we had about 500 referrals and in 2002 we had over 600 referrals. In a very small team this difference is very difficult to cope with. The team is very small. My position is only half-time. At least I have been told that we are lucky enough to have a geriatrician half-time. At least we have that half-time. A lot of other places do not have that facility.

My work is always a little different to that of other geriatricians because I do not have a geriatric bed and we do not have a geriatric department. All my work is focused into the community. That has done some good and some bad. I have written in my submission about how it has done some good. Some ways in which it has done some good is that we were always in the community and we did not have a lot of nursing home places. The reason we did not have a lot of nursing home places is that when we came in the Commonwealth had already made the rule of the 60 to 40 ratio. So our nursing home beds were always very limited. We had to make do with whatever was available in the community, so we really developed our community supports, and they work quite well. We also had a lot of other people supporting us, like respiratory workers, dementia workers and people who work with Aboriginal people. In that way we developed a strong support, and it did work.

Where we fall short is in the fact that, when there is a critical assessment, we do not have any bed to put them in to do the assessments. Other people have said, 'We do not have any psychogeriatric beds.' We do not even have geriatric beds to do assessments. Because I have worked here for so long and I have known a lot of physicians, I work very well with them, they are very cooperative with me and they help me. But there is always that stigma of the old people being bed blockers. No-one wants to admit them easily. Even if we say that we have enough support in the community for them and that we will do the assessment and take them out, people do not tend to believe us. So it gets a bit difficult to get these people into the hospital.

Unfortunately, for Aboriginal people in the bush areas it has always been difficult. It has never been easy. Take any branch of medicine, and that is the problem area. I am not going to say my area is any different. The only thing is that we have a little more help for those people in my area, so at least we can bring them here for respite. At least we can give them respite services. In

a year we can make sure that they are fed for two months by giving respite. Those things sometimes help. Medical problems in Aboriginal people are always multifold, because the combination of diabetes, hypertension, renal disease and respiratory disease is constant. I can write a blind history of any Aboriginal person and say that they have these four areas to worry about, and I will not go wrong, because most of them have these four complications. So any management becomes very difficult.

We have tried to keep people in their communities as long as possible. Because we have had strong community input, we could do that. As I said, these are the positives. Because Darwin is small, we all work together very well. So people who provide HACC services, people who provide packages and people who provide nursing home packages all work with each other. In big cities it gets very stretched and diluted, and it is difficult to work with each other because people do not know each other. We know these people, so it becomes easier for us to work with them.

They asked me to say what will happen in 40 years time. Forty years time at my age is a bit of an impossibility, because I am not going to last that long. But it is my wish that in 20 years time we could see these changes. I feel there needs to be a centralisation of the services. All the services work well, but they are so fractured. Each older person has to go to all these people in different areas all the time and answer the same questions. They could get fed up with these things. Most of the time the information we are asking for is the same, so I fail to see why we cannot have centralised services through which we can then disseminate the information.

Dr Lowe already touched upon the legal services. A lot of the time we are really limited in that we do not have the facilities to access guardianship or other things quickly enough to make the right decisions for the people. The other thing which is really a neglected problem in our area is abuse of the elderly. We find it so often. It burns out the people like us who are looking after the elderly; it burns out the other people who are identifying the abuse. But there is nothing mandatory we can do about abuse of the elderly. We just have to sit on it and do nothing a lot of the time.

The other thing is we may have to revisit the euthanasia question. The euthanasia question started from Darwin. I am bringing it back again, not because I am for it but because a lot of healthy elderly people are coming back and saying that we need some assessment of it and that they want to know the forward directions. There are not enough places or enough people interested in doing it. In 20 years time that will be one area we need to develop.

We need to develop a change in attitude, because you will hear that most of the nursing homes—I came in for the end of them—cannot manage because they do not have the beds and think like that. They are going to want more money. But if you talk to the elderly, they do not want to spend more money on their care. A typical elderly person says, 'I want to keep my money for my children,' or whoever it is. Unless the baby boomers change this attitude we are going to have difficulty in finding the money to develop better nursing homes and things like that. Over the next 20 years, we need to work on changing this attitude to one of: 'If you have money, it is for you; spend it on yourself.' Even I am going to find it difficult because that is not the attitude we grew up with, especially those of us who come from Eastern backgrounds. Filial piety is very strong in us: 'My job is to provide for the children and their job is to care for me.' It is well ingrained, especially in Darwin, where we have a very multicultural society. It is going to

be very difficult unless we change that attitude in the people. People are not going to be coming forward to spend the money on their own care.

Health promotion is another important area. I come from a public health background and I think that health promotion is a very neglected area. We need to have the elderly starting to keep fit so that everyone does not see them consuming a lot more of the health budget and needing a lot more medication and all that. I would try to do a lot more health promotion. I think that is the area that has to develop in the next 20 years if we are going to avoid spending a huge amount of money on medications and on acute health services.

Another area which I feel strongly about is geriatric care in the nursing homes. It has been recognised by many people in a few countries that geriatric care into the homes is quite poor. I have done this myself. Once the person is placed in the nursing home you forget about it. You go there the next time and you say, 'Who's this person?' when you have worked with that person for two months at a time. You completely forget about them. I used to read about an American view of having a person oversee all the aspects of a person's health care—skin care, osteoporosis, all the preventative factors, immunisation et cetera. They would go into the institution to make a visit once every three months to see all that was happening.

If we spent a little more money on that and saw that happening we would also avoid 'multipharmacy', which is a big problem. Any nursing home person would be having at least seven to eight medications at a time. No-one even really assesses whether they are really needed. We just keep on continuing them. The fault is on all of us at all layers. But if the country is really thinking of saving money on pharmaceutical products we need to start doing that.

CHAIR—Dr Mahajani, may I interrupt you for a second. Mr Mossfield and Ms Corcoran have to go, and I would like to give them an opportunity to question you before they do.

Mr MOSSFELD—I have a question for each of you. I was a bit concerned with your statement relating to the abuse of the elderly being traumatic and a hidden problem, and the fact that there is no solution to it. Basically we are here to try to provide solutions. Are you looking at domestic violence, as such?

Dr Mahajani—Domestic violence and financial abuse.

Mr MOSSFELD—That is important too, because there are many forms of abuse which we are not aware of. How could we itemise and document these areas of abuse so that some action can be taken?

Dr Mahajani—We could start documenting it. The problem we come across is who to give the information to. No-one wants that information: if you try to talk to the police about the abuse, they do not want to hear it; the social and welfare workers do not want to hear it because they cannot do anything with it. There has to be a way out. As with the abuse of children, if we hear of abuse of the elderly there has to be a definite pathway that we can go to. If the pathway were developed it would be very easy for people like us to direct the person there. It would also give us some protection because, if we start to even hint that there could be abuse, we become so unpopular that we never get entry there again.

Mr MOSSFIELD—I see the problem. Is that in both cultures?

Dr Mahajani—In all cultures. It is worst in the areas where children feel obliged, like in Greek and Italian families, to keep the people. They are suffering because they cannot really manage their elderly, but the culture is so strong that they have to keep on looking after them, and then these big problems start.

Mr MOSSFIELD—Even though they have not got the ability?

Dr Mahajani—It is shameful to accept the help, because that means the family cannot do it themselves.

Mr MOSSFIELD—That might be something the committee could look at and maybe come up with some recommendations. Dr Lowe, you made a statement about having a considerable number of people who would qualify for nursing home accommodation. Where is the blockage there? Do you liaise with the nursing homes?

Dr Lowe—No. ACAT comes every week and assesses our people. As the nursing homes were saying, low-level care is a problem, particularly the lower levels of low-level care. If they were recompensed more, then they might be more willing to take these people. As I was saying, we have a lot of people who are in that situation because they are single men living alone or they would have to be transferred back to living in a bus shelter or something like that. We have a particular problem with these sorts of people who need the lowest level of low-level care.

Ms HALL—Thank you very much for a very good presentation. I am interested in the availability of rehabilitation, how older people are linked into rehabilitation here and the need for them to travel south, outside Darwin, for rehabilitation.

Dr Mahajani—We have acute rehabilitation. People having acute problems get rehabilitation in hospital with the rehab team, but chronic or prolonged—long-stay—rehabilitation is not there. We have a facility, which is part of a day centre, which we have converted into a day therapy centre, so we try and carry on the ongoing rehabilitation there. However, it is difficult because of the usual problems. If a person has a dementia illness plus other illnesses, rehabilitation is very difficult. Acute rehab services will not accept them because they need dementia services.

Ms HALL—Dr Lowe, I note your paper, *Characteristics of a rural geriatric rehabilitation service*.

Dr Lowe—As I said, that was done in Lismore. We looked at whether we could provide rehabilitation services from Lismore to as far down as Grafton. We found that we were able to provide about half as much rehabilitation services even at those distances, which are nothing like the distances that we have here. The problem is that geriatric rehabilitation has to fit into the family and the community, and taking someone away to rehabilitate them can be counterproductive. So I am not sure how we will ever get remote rehabilitation services done here through a rehabilitation centre or something like that.

Ms HALL—If somebody has a serious head injury or spinal injury do they go to Adelaide?

Dr Mahajani—For spinal injuries, in the initial period they go to Adelaide, and then they can be brought here and attend daily rehab through the hospital. After a period, if they are elderly they get discharged to the therapy centre.

Ms HALL—Dr Lowe, I notice another issue you raised was about guardianship laws and the legal issues. In the other paper that we were supplied with a copy of, you talk about older people's competency to make decisions and how that is linked to that.

Dr Lowe—I did not know you had got these papers. As I understand it, there are a large number of applications for guardianship in the Northern Territory. They are very keen that the patients' rights are very carefully managed. We think the average wait for a guardianship hearing is about one to two years. An urgent guardianship application gets done in about two weeks. I think there is a very small office with just a few people and they have something like 300 guardianship orders at any one time. This is a state responsibility, but other states have better systems than this; they vary from state to state. If we have somebody in the hospital who insists that they will not go to a nursing home—which is quite common—and who clearly cannot manage at home and we need a guardianship order, that is not given any particular urgency, because, after all, they probably have worse situations in the community. So we might be waiting one to two years for a guardianship order before we can send someone to a nursing home. It is not run like this elsewhere. To have some coordination so that the best things from all the states are brought together would be very good as far as I am concerned.

Ms HALL—My next question is to do with the morbidity and mortality rates of the Indigenous population. Despite the numerous inquiries, reports and recommendations that have been done in that area, we find that not much has really changed and things are possibly even a little bit worse. What are the implications for Indigenous communities in the future, given the role that older people have traditionally played in Indigenous communities, if there is even further downward pressure on the age of the elders within Indigenous communities? What will that mean for the structure of those communities?

Dr Mahajani—I have visited a few communities—not in recent years, but previously—and there was a very distinct difference in the older people before alcohol was very common. Those elderly people, even now, are very well preserved and strong; they have respect in the community. Once they start drinking, they come to the city. They lose all that respect; they start getting sicker. There is a different trend from other societies in Aboriginal communities. Even if the younger people are drinking—they come into the city and live in the long grass and all that—if they want to look after the grandchildren they go back and some of them stop drinking. So the grandmothers are still quite strong in the community, and their voices carry.

Ms HALL—And the future?

Dr Mahajani—If they are going to be sick with all the other things then the sickness is going to catch up with them. They have very early strokes in Aboriginal communities—we find it so with all the ageing diseases. Many times when I sit across from a person who is 10 years younger than me I call them 'old man' or 'old woman' because they look old to me. So it is that much difference that you are looking at. Physically, they just get older much quicker.

Dr Lowe—Many of the elderly Aboriginal people are very impressive and they run lots of things in the communities and are responsible for lots of things—things like the painting movement et cetera. They are very impressive. If we could keep people alive longer, it would be a great boon to the communities.

Ms HALL—My final question goes to the ACAT team. The previous presenters to the committee highlighted that there was a wait for assessment. Would you like to share with us the reason for that?

Dr Mahajani—Because of the workload, which has increased so much, we have to categorise the people—for example, if we have to see them urgently, because they are falling or things like that or if something acute happens. In the last category, they are already in the institution and we just have to change the paperwork. Unfortunately, that has to be the last category, because it is not urgent for that person. They are already receiving some kind of services and things like that. So we try to accommodate the nursing homes, but we cannot make that a priority just for their financial benefit and say that we are going to let a demented person wait if they are running amok in the community. We cannot say, ‘We are not going to see them; we are going to see you first.’ We cannot do that. We have to prioritise our work. There are three categories of priorities in our work. The residential places, where we just have to change the categories from low to high, unfortunately come last.

Ms HALL—What are your priorities? How do you prioritise this?

Dr Mahajani—If the person has severe problems, the carer is burnt out and some needs are not being met or if a person in the community needs psychotropic medication acutely because they are very confused, those are our priorities.

CHAIR—Generally, are the specialist services for aged people in Darwin sufficient?

Dr Lowe—All the specialists in Darwin are also generalists, for the most part. We look after people of all ages et cetera. Apart from Dr Mahajani in the community, in the hospital there are not any specialist geriatric services.

CHAIR—I guess I realised that; I meant in general. Are the specialist services adequate in this area? I cannot imagine they would be in the rest of the Territory, but what about in Darwin?

Dr Mahajani—Are you asking whether we have enough cardiologists, respiratory physicians et cetera?

CHAIR—Yes.

Dr Lowe—No. Take for example a respiratory physician or a rheumatologist. Arthritis is so important in the elderly, and we do not have a rheumatologist.

Dr Mahajani—They are visiting; that is all.

CHAIR—As you quite correctly said, the guardianship laws are state laws. But are they really impacting on the ability of aged people to go back into the community?

Dr Lowe—They often impact on getting appropriate care. Yes, they are impacting enormously. The basic problem is people who are living in squalor and who are mentally incompetent, who need some placement and who do not want to go. They do not want to go, because they are incompetent—they are demented, brain-damaged or something like. In this case, attempting to look after people's rights through the guardianship law actually subverts their rights, because they probably have a right to better care than they are getting. I think it does have a negative impact. We can give an awful amount of anecdotal evidence of that, although perhaps nothing more statistical.

CHAIR—We will take that on board. I am very interested in your wish list, Dr Mahajani. I totally agree with your feeling that old people should spend more of their money on themselves. I suspect it is actually their children that do not want them to rather than them not wanting to. Obviously what you say about health promotion is very right: people might not need as many drugs et cetera. Have you ever expanded on that?

Dr Mahajani—I have started working only part-time because I like geriatrics. I kept on working with geriatrics after I turned 65. For the rest of my time I either work with Alzheimer's patients or NT Carers or any other agencies. I go and give talks to people about different things. What I hear from them is that so many people want the information and there are not enough of us to give the information. That is why I mentioned that: if there were some policy of doing the health promotion for the elderly, I think it would really go down well. People want that. There are a great many people really awakening now and wanting that information. We have a heated pool here, and all the elderly people go there religiously to keep their joints moving. But they need transport—they need some facilitation to get there. That is why I thought health promotion would be really beneficial.

CHAIR—I have one final question for both of you: given that the Aboriginal population does age earlier, do you find less dementia amongst the aged in that population?

Dr Mahajani—Dementia is less because we do not see a lot of them. We see quite a lot of dementia of people of other origins and it is multifactorial because of the head injuries and drinking. I do not know what we are going to see when we start getting the petrol-sniffers coming in. At present they are still young, but once they start ageing I do not know how much we are going to see that problem.

Dr Lowe—I think it is probably a slight misconception that they age earlier; they die earlier.

CHAIR—Sorry, that is what I meant.

Dr Lowe—It is important because they actually have specific diseases. We are putting them into a model of the aged care at age 50, which is not entirely appropriate. There are specific diseases: stroke, heart disease, kidney disease et cetera. For example, at Juninga people are there for renal dialysis rather than for specific diseases. The population just is not old enough to have a high prevalence of Alzheimer's dementia, although demented people do exist, but there is a very high prevalence of other forms of brain damage.

Dr Mahajani—The other thing is that to document dementia we really do not have any appropriate skills. For Aborigines we have started developing appropriate skills to assist

dementia patients. I think I am getting too cynical these days because I do not know whether they are going to be useful. We are certainly going to try them and work with them. In the Kimberley region we are going to try the same things out. To assist dementia and to categorise them the same way as we do with other populations is difficult because of the cultural language problem.

CHAIR—I thank you both. You have made an incredibly valuable contribution. I ask that somebody move that we accept the submission from Dr Mahajani.

Mr HARTSUYKER—I so move.

CHAIR—I thank you both very much for your time.

Dr Lowe—Thank you very much.

Dr Mahajani—Thank you.

[12.40 p.m.]

POOLE, Mrs Jane Elizabeth, Care Coordinator, Salvation Army With Care Program

CHAIR—I welcome the Salvation Army nursing home to today's hearing. I should point out once again that this is a formal part of the parliament and you should be aware of that in your answers. I invite you to make an opening statement.

Mrs Poole—The Salvation Army With Care Program provides extended aged care at home. I come from a background of working as a registered nurse within the nursing home for eight years. I spent some time over in the day therapy centre before moving across to the With Care Program in July last year. I will start by giving a brief outline of the nursing home and therapy centre from my role as care coordinator and I will be focusing on the EACH program.

The Salvation Army have operated a nursing home in Darwin since 1988. It is currently licensed for 50 residents. Sixty per cent of those are female, 40 per cent are male and 17 per cent identify themselves as Aboriginal. Of this 17 per cent, 75 per cent are from isolated communities and have minimal contact with a family or with tribal members. We are a high-care facility, with 25 per cent of our residents being category 1; 52 per cent category 2; 19 per cent category 3; and four per cent category 4. Our residents are from a wide range of ethnic backgrounds. As has already been highlighted, we have difficulty sourcing appropriately trained care and nursing staff and difficulty sourcing general practitioners who will come in and do home visits.

The therapy centre caters for an average of 20 clients per day and provides physiotherapy, occupational therapy, diversional therapy, podiatry and activities for elderly people who come to us for a rehabilitative service. Those clients live in the community.

The With Care Program is, as I said, the program that provides extended aged care at home. These care recipients and families have identified a wish to remain in their own home and not be admitted at this stage to an aged care facility. As I mentioned, the program commenced in July 2003 and we have 20 packages. Those packages are funded as RCS category 2. Twenty-six per cent of those are male and 74 per cent of our care recipients are female. Ten per cent are Aboriginal. Ten per cent have no living carer. Of those with a living carer, 35 per cent are cared for by a spouse, 18 per cent identify a son as their main carer, 35 per cent identify a daughter as their main carer and 12 per cent identify another female relative as their main carer.

One of the difficulties that we experienced with the program was that there was no start-up funding for the program and therefore it was initially difficult to purchase equipment to commence the program. As has already been highlighted, the aged care assessment team have their resource issues, which meant that it took six months before I had 20 clients identified as being eligible for an EACH package. The reason was that no extended aged care at home was available in the Northern Territory prior to July 2003, so everybody who was already known to the aged care assessment team had to be completely reassessed. We held network meetings with stakeholders to identify those potential clients who were at the limit of an existing CACP or HACC funded package and we then submitted that list to the aged care assessment team for assessment.

Another problem we have is that care recipients often have current services in place and wish to keep the service providers and carers that they have come to know, so the majority of our care is brokered through the previous service provider. The difficulties lie in us being able to liaise with the carers. On the whole, the paid carers who are in there from the other organisations work very well with us.

Since the commencement of the program we have had two deaths. Both of those were maintained at home on an EACH package until within 24 hours of their deaths, when they were transferred in an acute stage to the Royal Darwin Hospital. Two care recipients have been transferred to aged care facilities. The services that we provide are personal hygiene, domestic assistance, nursing services, meal preparation, medication management, respite care, social contact, transport, accompanying to medical consultations, gardening, pet care, provision of mobility equipment, light maintenance, occupational therapy and physiotherapy, and case management. That is all I have to say for now.

CHAIR—Are your day care services a recent development?

Mrs Poole—No, the day therapy centre is one of the first services the Salvation Army ran. It started off as a day care centre and transferred across in 1997, or thereabouts, to a day therapy based program.

CHAIR—And that is becoming a bigger part of your service delivery?

Mrs Poole—We have constraints on the size of the facility—for example, staffing resources and so on—but, yes, that is one branch of the Salvation Army aged care service delivery.

CHAIR—I will put it another way. Do you get the feeling that there is an expanding call on that, compared to some of the other branches of aged care?

Mrs Poole—There was more and more need for some rehabilitative therapy services to the aged population in Darwin, yes.

CHAIR—I am not sure whether you were here earlier when we were talking to the other services, but do you find that your permanent high-care and low-care beds are easy to fill?

Mrs Poole—We experience the same difficulties that the Uniting Church Frontier Services mentioned. We often end up poaching residents from each other. Initially, when a bed becomes available—

CHAIR—So it is pretty similar to what we heard before.

Mrs Poole—Yes, basically.

Mr HARTSUYKER—You mentioned the medication management part of the packages. Are you finding that package medication management is an effective way to deliver services? Even though you have various packs, do some patients perhaps still forget to take them or drop them? Is that an effective service delivery in that area?

Mrs Poole—It is part of the package of care that we can provide and, as another presenter has already mentioned, it is a matter of going in and prompting them to take those medications. It is the ability to know what they are on and to react as they experience symptoms from those medications, and it is liaising with the GP to be able to change medications as required.

Mr HARTSUYKER—But in relation to, say, medications that are required three times a day, that package would not normally involve you visiting the person three times a day, would it?

Mrs Poole—The majority of our care recipients are visited two to three times a day, yes.

Mr HARTSUYKER—You mentioned the shortage of capital funding for those packages. What are the sorts of things that you would use that capital for?

Mrs Poole—Because it was a new service to the Salvation Army, we had to purchase beds, lifting equipment, wheelchairs, various mobility aids, computers and a vehicle for me to use—basic start-up items.

Ms HALL—You are the only provider of the EACH program in the Territory. What do you think of it? How is it working?

Mrs Poole—I have been enjoying the challenge and getting to know the program more and more as I operate within it. I think it meets the needs. People on our packages are very pleased to be able to get those added services coming in, delaying their admission to an aged care facility. I think it meets the needs.

Ms HALL—Would you like to see it expanded? Is there unmet need in the community?

Mrs Poole—I think there is always unmet need, and it is a matter of being able to highlight what that unmet need is. As I say, it is a very new program. It is the first time I have worked in a community based program, so I am exploring those options as well.

Ms HALL—I would like to refer to a handout we were given this morning from the Northern Territory government. It was a letter from Masonic Homes Inc. I would also like to refer to the submission that was handed to us by the Northern Territory government. It showed that the cost of delivering services in the Northern Territory was 250 per cent above the national average. The letter from Masonic Homes Inc. showed that the RCS 1 that was paid for the Northern Territory with remote subsidy was less than Tasmania and Victoria and marginally more than New South Wales and the other states. Not only was that applicable for RCS 1, but also for RCS 2, 3 and 4. Would you like to comment on that and on the effectiveness of the RCS and the bureaucratic requirements that are associated with the RCS?

Mrs Poole—From an Extended Aged Care at Home perspective?

Ms HALL—No. I note your employment history—your association with aged care and the Salvation Army as well.

Mrs Poole—I support the comments that Frontier Services made about the impact of behavioural issues being only a small component of the RCS and the fact that behavioural issues

take up the majority of care staff and nursing staff time. I am not able to expand on them any more than that.

Ms HALL—Would you agree with what was put forward—that the costs of delivering services are 250 per cent greater?

Mrs Poole—I would not be able to comment on that.

Ms HALL—The other question I would like to ask you is about GPs and facilities for their visits. Maybe you would also like to comment from the perspective of those people involved in the EACH program. Have you any solution or ideas on how we can get around the problems that exist with getting GPs to visit residential facilities? Do you think that there is a need for GPs that work with older people to have some extra training in the area of gerontology or looking at the needs of older people? I know that it is a requirement in some, but not all, overseas countries for doctors that work with older people in nursing homes.

Mrs Poole—The first part of your question is how can we get the GPs to be willing to come out and visit people in aged care facilities.

Ms HALL—Yes.

Mrs Poole—I guess it is the Medicare fee structure that makes it difficult for GPs to financially justify being able to come out and see one person. They may be making a half-hour trip each way. Also, the time it takes to do the consultation can be the same time it takes to see three or four people in their own facility. If they see more than one person, the second consult is half the fee, which is then halved again and again. So by the time they see seven people, they are not getting very much money. We have explored options through the Division of GPs to try and do some case management type work with the GPs. I would not be able to comment on where that is at at the moment.

Ms HALL—Do you think that is the way to go?

Mrs Poole—If we can give the GPs a financial incentive to come out and spend the time—being proactive rather than just reactive in the care that they give—I think it can only be beneficial.

Ms HALL—Would that be a recommendation that you think this committee should make?

Mrs Poole—Yes. Access for GPs in the EACH package is not a problem. I have sent people to their GP.

Ms HALL—What about special training for GPs in the area?

Mrs Poole—That can only be beneficial.

CHAIR—I notice you mention here your links with the university. Was that in relation to residents wanting to further their education?

Mrs Poole—I am not privy to what you have received there.

CHAIR—In talking about your facility, it mentions that you have links with the Northern Territory University. I wondered in what respect that was.

Mrs Poole—We have nursing students who come through the facility on placement in aged care, and we have links with their tutors.

CHAIR—So, in other words, they use it as part of their training.

Mrs Poole—The placement, yes.

Ms HALL—Are care workers and qualified staff an issue?

Mrs Poole—Yes. Finding appropriately trained staff is an issue. There is the wage disparity between nursing homes and the public sector. Finding people who want to work is an issue. It is a specialised area and it is very physically and emotionally draining.

CHAIR—Thank you very much for coming to us today and for your information. I would like to thank all the witnesses who appeared today. Some of them gave up very valuable time to be here. I do thank you all for that and for the candour with which everybody addressed us.

Resolved (on motion by **Mr Hartsuyker**):

That this committee authorises publication, including publication on the parliamentary database, of the proof transcript of the evidence given before it at public hearing this day.

Committee adjourned at 12.56 p.m.