COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Aged Care

FRIDAY, 11 MARCH 2005

SYDNEY

BY AUTHORITY OF THE SENATE

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COMMUNITY AFFAIRS REFERENCES COMMITTEE

Friday, 11 March 2005

Members: Senator Marshall *(Chair)*, Senator Knowles *(Deputy Chair)*, Senators Humphries, Hutchins, Lees and Moore

Substitute members: Senator Allison for Senator Lees

Participating members: Senators Abetz, Allison, Barnett, Bishop, George Campbell, Carr, Chapman, Colbeck, Coonan, Crossin, Denman, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Forshaw, Greig, Harradine, Lees, Lightfoot, Ludwig, Mackay, Mason, McGauran, McLucas, Murray, Nettle, O'Brien, Payne, Tierney, Watson and Webber

Senators in attendance: Senators Forshaw, Knowles, Lees, Marshall, McLucas and Moore

Terms of reference for the inquiry:

To inquire into and report on:

the adequacy of current proposals, including those in the 2004 Budget, in overcoming aged care workforce shortages and training;

the performance and effectiveness of the Aged Care Standards and Accreditation Agency in:

(i) assessing and monitoring care, health and safety,

(ii) identifying best practice and providing information, education and training to aged care facilities, and

(iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;

the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly; and

the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

WITNESSES

Committee met at 9.03 a.m.

McGILL, Mrs Edna, Treasurer, Ethnic Communities Council of New South Wales

ACTING CHAIR (Senator Knowles)—I declare open this public hearing of the Senate Community Affairs References Committee which is continuing its inquiry into aged care. I welcome our first witness. The committee prefers evidence to be heard in public but evidence may also be taken in camera if such evidence is considered by you to be of a confidential nature. We also remind witnesses that evidence given to the committee is protected by parliamentary privilege. However, the giving of false or misleading evidence may constitute a contempt of the Senate. The committee has before us your submission. Do you wish to make any alterations to your submission or would you prefer just to make some comments before senators ask you some questions?

Mrs McGill—Yes. First of all, I thank you for the opportunity to be here. It was with short notice so I was unable to muster any of the forces. The person who wrote this submission has left us. The person who has replaced him is on a rural tour. The executive officer is in Paris and the chairman, who would have been with me, is working with the archdiocese in the Greek community. So it is me or nobody.

The Ethnic Communities Council is a peak organisation within New South Wales. We have a position there that is covered by DADHC with close contact with many New South Wales organisations and with researchers at the University of New South Wales. Professor Eisenbruck has had close links with us. Disability services are part of his role and he works with community organisations. So the information in the submission is not just plucked out of the air; it is from the amount of consultation et cetera that we have done.

We also have links with rural and regional groups and interstate ethnic organisations through FECCA, the federation, and ACROD. Our concern is to see that there is some sort of a national uniform approach to aged care rather than individuals doing lots of work. Sometimes that is dissipated and without coherent agreed policies. For that reason we have done a lot of consultation and that seems to be the agreed position at this stage. We want to see that national uniform approach to aged care rather than having individuals and individual groups doing a lot of work and replicating some of the things that are done without any agreed coherent policies. Our recommendations stress the need for the Commonwealth to provide leadership, planning and funding to achieve such policies, and you can see the number of recommendations along that line.

Our main concerns relate to cultural competency training for all staff and people who are associated with such places. Cultural aspects of care provision are important. Recruitment and retention of appropriate staff are always a problem. We would like to see some sort of overall planning about that sort of thing. With respect to young people with disabilities that we have mentioned in one of the recommendations, we must stress that putting such people into aged care facilities should be the last resort rather than just the automatic thing for young people who have no other avenues at this stage.

CHAIR—I apologise for being slightly late. I am interested in the community aspect of specific ethnic aged care facilities and the important role that they play. Do you see the role necessarily as one for specific ethnic groups or a mixture of that?

Mrs McGill—Those that were set up early in the scheme are doing very well. The Commonwealth has changed the way in which they are funding them by giving packages so that there is a grasping of packages. Where there has been a discrete group in an aged care facility it has made it a lot easier with regard to translation and interpretation because, as you know, as people get older they will revert to their first language. That makes it extremely difficult where you have a mixed group because if you have only got two or three of one particular language you cannot provide the language service 24 hours a day. It is better that way but we do understand that there are smaller groups, and smaller group associations, that would not have the facilities or the funds, I suppose, to support such a facility in addition to what the Commonwealth has provided. There is a big disparity now between the groups who have been here for a long time and those who have come in the last 10 years.

CHAIR—In relation to the community centres, especially the ethnic focused ones, do you find it difficult getting the number of bed licences that you actually need for the demand in competition with the commercial sector?

Mrs McGill—I think there are some difficulties. I do not work in that area all the time so I cannot give you any examples. But I think it is something to watch out for. The Chinese community have got several nursing homes in Sydney so we feel that they are working very well. The Greeks have got several homes. Those older big communities are well set up to support that. Even the Polish ones are well set up. There are no new Polish people coming in but I would predict that very soon some of those Polish facilities that are there now may lose people there. There is a big gap between the aged Polish group and any newer groups that are coming in and that would be replicated in some of the other communities, too.

Senator KNOWLES—I just want to discuss some of the areas that you were talking about then. I have dealt a lot with the Greek, Italian and Chinese communities—a whole range of communities—with their individual facilities. They are outstanding facilities in every way, shape and form. How would you suggest planning should be undertaken to deal with a lot of these communities in isolation when it is hard to predict the numbers that are needed to go into an ethno-specific facility and planning has to take into account the broader community?

Mrs McGill—You are talking about the difference between the large communities and the small communities?

Senator KNOWLES—I am talking about the difference between any of the ethno-specific communities and the broader community in general.

Mrs McGill—I think there is a tremendous difficulty there. What we do not want to see is an attempt to obtain more government funds than we are likely to get. But we would perhaps see that there would be small units within a big facility that would look after certain groups. I would acknowledge that that would take a lot of planning and a lot of investigation.

Senator KNOWLES—It would be duplication, wouldn’t it?

Mrs McGill—Yes, that is right. It would certainly be a difficult task yet I think it would be a good task to have a look at. I think that is part of the notion that we are talking about: understanding the need for good forward policies. The Lithuanians and the Danish and other Scandinavian peoples have very small groups now, and yet through their churches there are still facilities available on a smaller scale than those such as the Greeks and the Italians. It may be that it is possible to have small units, even if they are not in the same particular hostel or facility, but recognised as being for particular groups.

Senator KNOWLES—Could I just clarify that. What you are saying is that it may not be necessary to have them as stand-alone units but that we could try and incorporate them into the general facilities?

Mrs McGill—I am being pragmatic. Obviously I would rather have a particular language group together and for them to have their own facility, but, pragmatically, I do not believe that that is going to happen for some of the really small communities. I think we have to acknowledge that they need their care in the same way as the larger groups do and that we have to be very sensitive as to what is provided for them and where those facilities might be. So I suppose it is like wards in a hospital. That is a bland way of putting it, I suppose, but it could be looked at in that way. There are surely figures available that will show that in, say, five or 10 years there will be certain age groups within particular communities who probably will want those sorts of facilities. I guess that comes back all the time to whatever policy the Commonwealth looks at, how realistic it is and how it will be achieved to the best possible advantage of the people involved.

Senator KNOWLES—Moving on to a comment you made during your opening statement that nursing homes should be a last resort for young people, I do not think anyone would disagree with that. What I would like to know, if you are able to tell us, is what the ECC has done with the state government to try and get more specific accommodation for younger people who should not be in nursing homes.

Mrs McGill—In our submissions to the state government, we have tried to build that sort of pathway, if you like, for people. It is really sad when a young person who perhaps has all their faculties but is immobile is put into an aged care place.

Senator KNOWLES—It is very difficult for the older people too.

Mrs McGill—Absolutely. It is not a good mix when people are at that stage of their lives. I am not talking now from the ECC’s point of view. My daughter happens to work with young people with disabilities. A lot of that work is done out of state funds, but it is never enough, and I do not believe it is done with an overall view of these things. I think in those instances the Commonwealth may have to work with the states to add to the policy notion of what you do with people who are incapacitated.

Senator KNOWLES—That is where we are in a difficult position with an inquiry such as this. The responsibility for accommodation for younger people with disabilities rests with the states.

Mrs McGill—Yes, I understand that.

Senator KNOWLES—We have, unfortunately, instances where state ministers are making personal representations to the Commonwealth to allow younger people to go into aged care facilities, which is an admission that they have not got enough. I come back to my original question—and I understand that you have given your personal view from your daughter's experience—and I just wonder what the ECC has done to try and get the state government to provide more accommodation for younger people with disabilities.

Mrs McGill—We are constantly on the move in that direction. Last year we met with the minister and we put that position to the minister. We meet with the state Treasurer each year. Whilst we do not always talk about those sorts of things, certainly we work with NCOSS. NCOSS puts forward a great submission to the state Treasurer each year and they go through all of those things. We are only allowed three wishes, so sometimes we cannot cover all the areas in which we are involved. We work collaboratively with both the Council of the Ageing and NCOSS when we go to the state and try to divvy up, as it were, what we are going to ask the Treasurer to give.

Senator KNOWLES—The wish list.

Mrs McGill—Yes, that we get nine wishes instead of three.

Senator KNOWLES—So ECC has not put in a submission in its own right for a possible solution?

Mrs McGill—I am not really aware of that. I know that it is mentioned in the submission that was written by Patrick Harris. I think that he has taken that up. I know that a number of letters have gone backwards and forwards between the ECC and the minister. I feel quite confident that that would have been raised on some occasions but, as you would probably be aware, sometimes it is difficult to get an answer from government people.

Senator KNOWLES—I cannot believe that! I wish to ask one more question about the aged care accreditation standard—recommendation 8. The author of your submission did not particularly go into any great detail about the way in which it is suggested that it be amended to include the specific consideration of cultural aspects of care provision. Do you have any information on that recommendation?

Mrs McGill—Not about that particular recommendation, but it falls into line with the things that we do all the time—that is, we try to get that cultural competency into every sphere of the work force. It does not necessarily belong to non-English speaking people; it belongs to people from all sorts of cultures, whether they were born in Australia or not. We believe the aim of the cultural competency is to make people who work with other people—particularly in these close relationships with other people—understand that their culture is different from the culture of others and they must not treat these people as less than human beings who will demand their respect.

People from the Department of Community Services, people in the education sphere and people in all sorts of workplaces do have available training in cultural competencies. You can call it something else if you like, but that is the notion of it. I guess we are pointing out that it is super important that, where you are dealing with somebody who is ill, aged or incapacitated in any way, you need to have an empathy with, an understanding of, where that person sits. As I said before, particularly with the aged, you have people reverting very strongly to their first culture—their first language. Unless there is somebody there who can take that on board—even if they do not have the language themselves—you are setting up a very nasty situation.

Senator KNOWLES—I do not quite understand the recommendation that the standards be amended to specifically consider cultural aspects of care. Virtually all of the facilities that I have ever visited that are of NESB or different cultures have a great awareness of communication and food. Take the Jews as an example. The Jewish aged care facilities are fantastic in that respect because they will cook kosher meals, non-kosher meals or whatever. I am not quite sure what that really means.

Mrs McGill—I think it means that, whilst these are aged care facilities that are run by either religious or community groups, they will take that into account. But where they are getting their packages for other groups, they may not understand other cultures. It needs to be generalised. If somebody is employed in these places they have to be sensitive to everyone. It is not just the Jewish; it is the Chinese. I suppose for the Chinese, all of the staff would be Chinese; for the Greeks, all of the staff would be Greek. But the Greek home that I visited not long ago was going to take in some Polish people. It was only a handful of people. When you ask: ‘Will there be somebody of Polish origin available for them around the clock?’ they say, ‘Yes.’ But you are not going to have three or four shifts of nurses or staff that can speak Polish. It is just not economical. I guess that is where we come back to whether it is better to have them as distinct groups—language groups, cultural groups—or whether you can mix them all together, and how that affects them.

Senator McLUCAS—You made some interesting comments about bilingual workers. I was unaware of the Community Language Allowance Scheme. Is that a state government program?

Mrs McGill—The Community Relations Commission has an interpreting and translating service, which is very good, but in some working relations positions there is an allowance for community language. I cannot swear that it is in every nursing home because I am not familiar with it, but one would hope that that would still be around.

Senator McLUCAS—The submission says it is available to state government employees. It must be just for state government employees.

Mrs McGill—It is for state government employees, yes. That is the point I am making. I know that it is in a number of areas and in hospitals, but I honestly do not know whether it is in aged care.

Senator McLUCAS—Then you talk about interpreting. Who pays for the interpreters? If you are in a circumstance where you are contacted by a residential aged care facility that is not ethno-specific and someone is in need of translation, what do you do?

Mrs McGill—If somebody asks our advice, we point them to the two facilities that are available. One is TIS through DIMIA. That is charged. Transcultural Mental Health has good translation services as well. There is also the Community Relations Commission. There would be instances where there would be charges for it, and I would assume that the nursing home, or whatever facility was asking for that, would do so. Each government department in New South Wales, some few years back, was complaining about the cost of translations et cetera. They had to apply through the Premier’s department, I think, or somewhere else, to get it. Then every school was given an allowance, but it has disappeared into their budgets, so they do not notice it anymore. We constantly have to remind them, ‘Hey, you’ve got that somewhere. It might not have been indexed over the years, but it’s there.’ It is expected that state government organisations would be using translators where it is necessary. The state one under the Community Relations Commission is very good. In all courts, for example, they must have an appropriate interpreter.

Senator McLUCAS—In recommendation 4 you talk about the ethnic aged care framework. I am interested in your comment about a shift from a program framework to a policy framework. Did you want to give us more information about what currently exists and what should exist?

Mrs McGill—I cannot give you the details. I am terribly sorry about that.

Senator McLUCAS—That is all right. Do not apologise.

Mrs McGill—It was short notice. From my reading, making it a policy would certainly mean that everybody would have to adhere to it. If it is just a program, you may or may not follow through in that way. That is the whole basis, as I read it, of this submission. If the Commonwealth can look at the whole picture and make some very definite guidelines or policies, it will be easier to police them. Organisations like ours can then say, ‘Okay, you should read what the guidelines are. You should see what the Commonwealth policy is on that.’ That is why we are asking you to, after you have done all of this, have a look at all the things and see what people are asking for.

Senator McLUCAS—Is that so that all residential and community aged care would have an understanding of cultural difference and an understanding of how to accommodate people from culturally different backgrounds?

Mrs McGill—Yes. We have been through this over the years with education. I worked in education for many years. It was really a matter of training every director, every consultant, right across New South Wales—all of the people who were having an influence at the school level. It was hard in the beginning, because you do not always come to an adjustment in the way you approach things just by osmosis. You really have to be nudged from time to time. I think that is replicated across other areas. I used to say about education, for example: imagine it is day 1, term 1, you go into the classroom, 30 little smiling faces are looking up at you, hardly any of them speak English and they might have 10 different languages—what is the first thing you do? I can translate that into an aged care facility in the sense that if it is not language specific you might ask the same thing: what is the first thing you do? How do you go about communicating with them? How do you listen to what they have to say and how do you make their life easier?

Senator McLUCAS—Thank you very much.

Senator LEES—In recommendation 14 you talk about the lack of information and data on the ethnicity of clients. In terms of forward planning, what material is your organisation able to get access to, in terms of information on which specific language groups in particular will be needing support in, say, 10 or 15 years time?

Mrs McGill—Data collection and so on rests very strongly upon the census, whether it is the ABS figures with respect to where we are at now—what our communities anticipate and what the forward planning is there. We need to have that sort of data disseminated and to have the Commonwealth and the state agree on what we are facing in 10 or 15 years time.

Senator LEES—If you have, say, information that there is a particular group within the next 15 years that is going to be requiring some very specific support, are you able to then work with some of your member organisations to reorganise an existing nursing home or apply for additional beds? How does the process evolve?

Mrs McGill—We do not have that capacity. Our membership comprises very stand-alone organisations. We can disseminate information and we can consult with them, which we do across Sydney and across New South Wales, but unless they have somebody there who is driving that, some of the communities themselves cannot anticipate that. That would be our aim now. Robert is in the west of the state trying to pick up that sort of information from town to town. We will continue to do that. We have ethnic communities councils in Newcastle, Wollongong, Wagga Wagga, Griffith and Lightning Ridge. I talk with them quite a lot. Newcastle and Wollongong in particular have ageing populations and, to the best of my knowledge, there are no particular language-specific groups there. They do a lot of day care for their aged people. I think there is a lot more work that needs to be done in this respect and hopefully we will be continuing to do that with Professor Eisenbruck.

Senator LEES—If your organisation, say in Newcastle, recognises that there is a group in, say, 10 to 15 years time that is going to move beyond home care and is going to need nursing home support, how difficult is it to organise a language-specific facility? Or, given the pressure on nursing home beds, is it a matter of chance if they can actually get into a home? In my home state of South Australia we have a large group at the moment occupying nursing homes—the German population, particularly in the mid north of Adelaide through to the Barossa. The younger population of that group will not need them at all. The situation has evolved over the years such that in one nursing home German language is spoken and very little else. But, given that some people have to agree to their relatives going to nursing homes maybe 15 suburbs away if not almost beyond reach because of the scarcity of beds, how difficult is it once you have identified a need to actually be able to create a facility that is culturally appropriate?

Mrs McGill—It is very difficult. I empathise with the Germans. We have Polish people out at Marayong in the western suburbs. There are very few Polish-born people who in 15 years will need a nursing home. That facility is attached to the back of the church. There are quite a few others in the same situation—for example, the Lithuanians at Engadine. I do not know how many aged Lithuanian-born people there are going to be in a few years time. What will need to be looked at—and maybe we can try to do some research on it—is how those particular facilities, if they are still good facilities, can be used for other groups.

Senator LEES—How they can evolve into a new language group?

Mrs McGill—Yes. But if they are owned by the church, it might mean twisting a few arms.

Senator LEES—Thank you very much.

Senator MOORE—Years ago, there was a promotion of a program for ethnic specific aged care. It was in about 1991-92. At that stage, there were people within the departments who were particularly looking at this issue because of planning. Are you aware of whether those positions are still in place in the federal Department of Health and Ageing and also at the state level—where there are actual workers within the structure whose sole responsibility is issues to do with ethnic groups?

Mrs McGill—I think that the emphasis has changed from encouraging groups to set up a hostel or care centre that is specifically for that one language to offering packages. We have six Greek ones coming up. Who is going to bid for those? Greek is a bad choice because there are enough Greeks around to fill a number of nursing homes. But I feel in a sense it is a pity. In some groups—maybe some of the eastern groups: for example, Burmese people—where will they go? There will not be enough Burmese to set up a whole facility. That is part of the planning process or the policy that we are asking you to have a look at. We hesitate to tell you how to do that, but it will be a problem because we have so many. We have 46 or so different language groups around.

Senator MOORE—With whom do you speak in the departments—state and federal?

Mrs McGill—At the state level we talk to the minister and we talk to people in DADHC. We have a number of people there, from the director down, who work with our officer. At the federal level we do not have anybody. They funded two positions a few years back.

Senator MOORE—They did.

Mrs McGill—They no longer fund them. That is a pity in the sense that if they are not funding anybody at the state levels they will not be getting any sort of community responses there. That might be something we can look into.

Senator KNOWLES—I have a further question about quality complaints. Do you get any quality complaints?

Mrs McGill—Not personally—not at our office. There could well be complaints to people who are working in the field. Perhaps later in the day you will talk to some people who work closely with them. The complaints that are generally there are mainly from the family of those in the facilities. I was going to say I had a complaint recently, but that was about the Guardianship Board, which is another matter that we have to watch very carefully—what guardians actually decide and who does the muscling work on the guardianship of people who are not capable of making their own decisions. I am sorry I could not answer your question very well.

Senator KNOWLES—Thank you.

Mrs McGill—Thank you for your forbearance.

CHAIR—Thank you.

[9.39 a.m.]

BARTON, Associate Professor Michael, Chair, Neuro-Oncology Group of New South Wales

LANGFORD, Mrs Siobhan, Member, Neuro-Oncology Group of New South Wales

SIMPSON, Mrs Teresa, Member, Neuro-Oncology Group of New South Wales

HODGKINSON, Dr Adeline, Director, Brain Injury Rehabilitation Unit, Liverpool Hospital; and Director, Greater Metropolitan Clinical Taskforce, Directorate for Brain Injury Rehabilitation Network New South Wales

STRETTLES, Ms Barbara, Residential Service Manager, Brain Injury Rehabilitation Unit, Liverpool Hospital

CHAIR—Welcome. Do you have any comments to make on the capacity in which you appear?

Mrs Langford—I am a senior social worker at Neurosurgery at Liverpool Hospital.

Mrs Simpson—I am a social worker with the Cancer Therapy Centre, Liverpool Hospital.

Dr Hodgkinson—I am currently the director of the Directorate for Brain Injury Rehabilitation Network set up under the GMCT, a state-wide clinical focus group for the network for brain injury rehabilitation across New South Wales.

CHAIR—The committee prefers evidence to be heard in public, but evidence may also be taken in camera if such evidence is considered to be of a confidential nature. Witnesses are reminded that the evidence given to the committee is protected by parliamentary privilege and that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee has before it your submissions, and I now invite you to make an opening statement, to be followed by questions from the committee.

Prof. Barton—We would like to thank the committee for the opportunity to present to them. The neuro-oncology group is a small group of clinicians, both doctors and members of allied health, who are involved in the care of people with brain tumours. Brain tumours in New South Wales and around the country only constitute about two per cent of all cancers but they are cancers which more frequently affect young people, and the group that we treat tend to be young people. In New South Wales there are about 400 or 500 new cases a year and about 280 to 300 are people under the age of 65, and it is this particular issue that we would like to talk to you about.

Around Australia the figures are about 1,400 new cases, 800 of which are people under 65. Nearly all of these people will die of their cancer, so we are talking about people whose cancers arise in the brain and they run a course that on average lasts about a year, sometimes up to two years. As you can imagine, the brain is a fairly important organ and damage to the brain can have major effects on people’s ability to function normally and, particularly for young people, there seems to be a major lack of services. In our area health service, for instance, we have no long-term palliative care beds. Palliative care beds are available only for people who are dying in the next few days or weeks, so there is acute palliative care but that is it. There is very little home care, and the home care services are run by the aged care groups. This is a very labyrinthine and difficult area to work your way through, and I asked these two professionals to come with me because it is their full-time job trying to sort this out. Perhaps it would be better for Siobhan to explain what happens to somebody who is at home who needs care and what the barriers are.

Mrs Langford—The biggest barrier at the moment is waiting lists. When people are in imminent need of receiving care, the service is not available. The packages that would be of benefit to young people are funded through the federal government for elderly people such as community aged care packages or Extended Aged Care at Home. At this stage the best structure we have for people is a six week short-term package called ComPacks, which provides up to 10 hours of care a week for up to six weeks maximum and is generally not enough. Coupled with that, we have got costs for equipment that people have to have in their home to have care provided safely for them, and these costs are normally quite prohibitive if they have got to hire it from private companies. The biggest problem for the young group is that they have often got mortgages, families or other financial commitments and the pension they receive, if they are eligible, does not cover everything and give them the quality of life they need at home. So that is one of the biggest problems with services.

Dr Hodgkinson—Thank you again for the opportunity to speak to the inquiry. I will just give you a little description of the brain injury rehabilitation service at Liverpool. We have had 28 years of experience in brain injury rehabilitation, beginning at Lidcombe and moving to Liverpool with the opening of a new unit there. We are part of a statewide network which involves two other in-patient units, two paediatric units and several rural units. Each year we place three to five per cent of our patients in a nursing home, and another five to 10 per cent of patients with a similar disability go home, despite the lack of adequate, appropriate services for them in the community. We looked in more detail at the people going through our unit and being placed in units. As a rough estimate, I think this is about 15 to 20 per cent of the statewide focus. The average age was 39, with the youngest being 19.

We placed 25 people in a nursing home between 1999 and 2003. It was not our decision; it was the family’s decision. At the point of discharge, when we have finished our rehabilitation phase, which is an acute service, we need to move people on. Families and relatives are given the option of deciding whether to take the person home with what is clearly inadequate support or to place the person in a nursing home. This is a difficult decision for the families, and it comes at a time soon after the acute phase. It may be six months or it may be 18 months post injury, but nevertheless the families have not really adjusted to the severe and catastrophic nature of the injury itself. They are being asked to make a decision about whether they will care for the person at home, with perhaps three to five hours of attendant care a week, which is all that is available under home care, or—to look after their own mental health—place the person in a nursing home, where they can see a young man sitting next to a sea of 80-year-old faces. It is a difficult and distressing time for the families.

It is also very difficult for us, yet we have no alternatives. As a health service we need to continue to provide acute rehabilitation for newly injured people, and therefore barriers to discharge are a significant issue. Nevertheless, we take into account people's desire to manage the person at home. We will often work extensively with families, writing submissions—often quite fruitlessly—to various state and Commonwealth departments for assistance in care.

Why does the situation exist? I believe that it exists partly because there is a state and federal distinction. As soon as a person is admitted to a nursing home, he or she is no longer a responsibility of the state. As soon as a patient is discharged home, there is no federal responsibility to assist in the care and management of that person in the community. The other issue is that, at a state level, there is also a battle between the Department of Health and the Department of Ageing, Disability and Home Care, in that while a patient is trapped in a hospital waiting for a service they are not a cost or responsibility of DADHC, and once they are in the community they are not the responsibility of Health.

What have we done? As a service, we have continued to advocate for and support our patients and their relatives in whatever accommodation source they choose. We have made presentations to state government. In 1993 we conducted our own survey of people within nursing homes. We have participated, and Barbara Strettles has been involved, in a long-term care project funded by the Motor Accidents Authority, looking at those in nursing homes and the alternatives that would be available to them.

We have done the submission to this inquiry and we have met with DADHC and the Brain Injury Association. We have also put in two applications for the innovative pool of funding, but neither of these submissions has left the state. In different years they have been held up for different reasons. One was a lack of the ability to commit to a planning process at a state level and the other one was that after our submission was put in the terms of reference for the submission were changed and it no longer fitted.

There should be suitable options and alternatives to nursing home placements for young people. This can occur within the compensation system. A number of current patients were injured in a motor vehicle accident and a no-fault long-term care option, WorkCover and third party, for patients injured in accidents would remove a number of people from the needy group. This is important to support at a state and federal level. There should also be public funding which recognises people with a traumatic brain injury as a special needs group. They do not fit easily into group homes or community living arrangements for developmental disability and certainly not for the mentally ill. There also needs to be a rehabilitation focus, as these are acutely injured people who may after an acute phase of rehabilitation make gains in adaptation to community living and end up needing much less care at five years post injury than at two years post injury. That is an important part of any service that looks at the needs of traumatic brain injury.

Accommodation facilities should be age and peer appropriate and I believe it is both a state and federal responsibility. The accommodation can meet a variety of different needs, varying with the level of severity of the patient and the community supports. For example, a special needs focus in a nursing home local to the family of the patient is important. There needs to be community living arrangements which are supported accommodation services. There should be individual support, perhaps at a lesser level for someone living independently, or carer support for those being cared for predominantly by their families. I think that is all I needed to say.

Senator KNOWLES—Professor Barton, would you mind expanding a little if you can on the age breakdown? I think you said there were 1,400 people with brain tumours across Australia, 800 of whom were under 65.

Prof. Barton—This is the latest data from the Australian Institute of Health and Welfare that gives you a breakdown—sixty per cent of new cases of brain tumours and 53 per cent of deaths from brain tumours were in people aged 64 or younger. We do see that younger people tend to survive a bit longer. In fact, in my clinical practice, about 85 per cent of the people that we treat are younger people, people under the age of 65.

Senator KNOWLES—I am encouraged to know that under 65 is classified as young.

Prof. Barton—They are the group that do not qualify for the over 65 benefits. I think I said ‘younger’.

Mr ABBOTT—That is right, but in general terms in this inquiry we have been hearing that under 65 is now considered young and, as I say, it thrills me no end.

Prof. Barton—You have less grey hair than me.

Senator KNOWLES—I might have help. The thing that I am trying to focus in on as well is the people who are what I would consider younger—those in their teens, 20s and 30s.

Prof. Barton—I can give you those figures straight off. The cumulative total of the group up to the age of 20 is 10 per cent of all tumours and that of the group up to the age of 30 is 14 per cent of all tumours—in other words, about five per cent of people in the 20 to 30 age group. People up to the age of 50 make up 42 per cent of tumours. So you could take 10 per cent off. Brain tumours are in fact the commonest solid tumours in children.

Senator KNOWLES—Are they?

Prof. Barton—Solid tumours, not leukaemia. The special needs of children have already been recognised. The needs of young adults and even people, as we have said, up to the age of 64 are not really well recognised and not well supported. The ability of people to stay at home is very difficult, as we have heard. We have a problem of changing needs all the way through the trajectory from diagnosis to death, and people who are well at one point are not well a bit later on. They will go in and out of hospital. Most of them will never quite make it to palliative care, because they often have very sudden declines. They place enormous burdens on their caring support services. We worked out that it would cost something like $10,000 a year just to get the equivalent of a bed and some other facilities that you require before you can get home nursing. This is on top of losing your income and probably your carer losing their income while they are looking after you.

Senator KNOWLES—What is the prohibition? Where is the cut-off in being able to qualify for home nursing—the Silver Chain type nursing? I am from Western Australia, and I think Silver Chain is only in Western Australia.

Prof. Barton—I do not think we are as rich in this half of the country. It is 64-65, isn't it? It is over 65.

Senator KNOWLES—But there are younger people at home who are getting home nursing on a daily basis.

Dr Hodgkinson—One of the difficulties is the rationing of the home care nursing. A patient who requires two people to lift or transfer them is eligible for 2½ to three hours of care a week; that is the rationing amount left. If the care is only for one person, they may get five to seven hours a week.

Prof. Barton—I do not think we have made a successful referral to home care in the last couple of years.

Mrs Langford—I know that I have not, personally.

Senator KNOWLES—What are the reasons that are being given to you?

Mrs Langford—Budget. Home Care is geographical. In the south-west, where I make a lot of my referrals, we are told that that area does not have the funds. However, if the client lived in an area that did not have as high a need for home care, I would be able to get them a service, and then it is that rationing, again—only being able to provide three hours and trying to stretch the dollar to get to more people. Home Care does not take waiting lists; they take expressions, I guess, of need, so if a family rings up again in a few weeks or in six months, they can try again but there is still no guarantee that there will be money there. We are not really given a satisfactory reason.

Prof. Barton—If you are only going to live five or six months, or even a shorter period of time, you often do not make it through the waiting list.

Dr Hodgkinson—There are two other options. There is an attendant care program, which is designed specifically for people with spinal injury. The criterion for that service is that the individual requiring care must be able to direct their own care. Someone with a severe traumatic brain injury is not in a position to direct their own care, even if they have a father, mother, husband or wife who is quite capable of directing appropriate care, so they are ineligible for attendant care programs. The other option is the high needs pool of home care funding for which, last year, I was told there was a three-year waiting list. You cannot really wait three years for a high-needs care pool position. It was previously under SAS funding, but that very quickly became overloaded and collapsed under the weight of the needs. They granted temporary funding on a three-monthly rotation, and you had to reapply every three months.

Senator KNOWLES—The Neuro-Oncology Group's submission says that palliative care is not considered to be the ideal option, because the hospitals tend to try to push people through more quickly than some of the acquired brain injured people. Surely the palliative care option is a far superior option to people being pushed out and basically asked to fend for themselves.

Prof. Barton—Our palliative care service is an acute service, as are a lot of palliative care services around the state. That means they will take only people with acute short-term problems and people who look like they will die in the next couple of weeks. If somebody is going to be there for three or four months they will find a nursing home for them if they can.

Mrs Langford—And to make sure the beds keep moving, families are often asked to sign a nursing home form prior to entering a palliative care unit. If the person does survive beyond the three or four weeks, they will have to move on to a nursing home.

Prof. Barton—Basically, there are no suitable nursing homes. Adeline put this very well: there are just not the facilities for either the type of care or the social environment that our patients need. We are basically locking them up and throwing away the key.

Senator KNOWLES—Dr Hodgkinson, you made the comment that there was a bit of argy-bargy going on between the state Department of Ageing, Disability and Home Care and the state Department of Health, and that you had presented your case to the state government. Was that in a written or formal form? How long ago was that?

Dr Hodgkinson—In 1999 I was invited to present, along with the Brain Injury Association and other people, to the Legislative Council. That really resulted in no change. I could give the same speech with the same case examples. Nothing has changed in that time. With the Brain Injury Association, which is an advocacy group, and other directors of brain injury units I have met with senior officers in the Department of Ageing, Disability and Home Care. I was basically told that my appropriate mode of advocacy was through the Department of Health and they would meet with the Department of Health executive and work with them. Meetings are continuing between the Department of Health and the Department of Ageing, Disability and Home Care but what we do not see is any action, any funding or any change. I have been working in the brain injury unit now since 1993 and I could not say that there is any more available in the community to assist people—either managing them at home or, if they are accepted into a nursing home, breaking down those barriers of access outside a nursing home. A young person who may benefit from going to a day group with peer-appropriate activities still has barriers to that access.

Senator KNOWLES—Do you have copies of any formal submissions you have presented to the state government that you would be able to provide to the committee?

Ms Strettles—Last year we started meeting with our regional branch of the Department of Ageing, Disability and Home Care and we developed a submission for our interdepartmental committee at a regional level—south-western Sydney. We have that available. We started to do that because we were getting nowhere at the state level and we were advised to try at the regional level. We were trying to develop the submission with the regional Department of Ageing, Disability and Home Care and the problem was that the brain injury group was not identified as a special needs group so we could not be seen as advocating for a special needs group. We could not jointly present the document and put our name on it as a joint presenter because we could only represent the views of young adults with disabilities; we could not represent a special needs group. This was quite distressing after we had gone through a few months of trying to put forward a proposal to the interdepartmental committee at our regional level. We had hoped to improve the profile of government cooperation, and work across departments with Health, DADHC, Education and Housing.

Dr Hodgkinson—We were told at the state level that the identification of brain injuries as a special needs group was a federal decision in relation to the funding that goes through to the state Department of Ageing, Disability and Home Care and that there were five special needs groups, of which brain injury was not one—or palliative care, for that matter.

Senator KNOWLES—I do not understand any of that—other than a bit of buck-passing.

Dr Hodgkinson—They can fund generic disability services, of which the vast majority are developmental disabilities. Therefore they cannot specifically address the needs of anyone with a traumatic brain injury who has very different needs in terms of their behaviour, their prior life experience and the recency of those problems.

Senator KNOWLES—I understand that side of it. What I do not understand is where the state department is shifting the responsibility backwards and forwards, other than a bit of buck-passing. We are trying to get to the bottom of all the funding of state and Commonwealth responsibilities so that we can get to the sharp end of service delivery. That is why I asked whether there was anything that you could usefully provide to the committee about the case that you have put to the state. I do not quite understand the difference between dealing with a state department and going in at the regions, because I would have thought the regions still come under the auspices of the state.

Dr Hodgkinson—I think we could give you our experience as a document. It really is another example of where we have got nowhere in effecting change.

CHAIR—We would appreciate that. I appreciate that your submission was made last year, but you talked about a nursing home research project that you were undertaking. Has that been completed and is that available?

Ms Strettles—Unfortunately, that has not been completed. It has taken longer to write up than expected. The report is in its final draft form and should be available in April, if that is not too late for the committee.

CHAIR—That will not be too late, if you can make that available.

Senator LEES—You are talking about state processes, where states have made arbitrary decisions about what is in and what is out. The committee was able to visit a specific facility for Huntington’s disease in Perth. It looked much like any nursing home but it had been somewhat modified. I think if they had had the plans from scratch it might have been different, but it was a specific facility. We visited one specific facility for young men with acquired brain injury, which was again quite similar to many nursing homes, and one for MS, which looked exactly like a nursing home that I had recently visited in Victoria.

From your experience on that side of the problem, why can’t we just look at however many nursing home beds are in the system for New South Wales? Presumably in a year there would be another 30, 40 or perhaps 100 released. Could they simply be put across to young people, therefore releasing other nursing home beds into the aged care system, with the state government agreeing to cover the additional running costs for people with acquired brain injury who are going to need a lot of very specialist care? Instead of aged care packages, perhaps we should talk about high needs packages. From your side, what have been some of the excuses or reasons that you have been given for why we cannot simply divert the next group of New South Wales aged care beds into long-stay beds or rehabilitation beds?

Ms Strettles—In New South Wales we have an extremely long history of not being able to break down the barriers. I have a longstanding working history in the field. At various times, people tried to set up clusters in nursing homes, and then nursing homes were threatened with loss of funding for those beds because they were aged care beds and because they could not actually get an extra category in the aged care brief to fund the care of young people whose needs were different.

Senator LEES—So we need to change that. On our side of the table, that is a job for us.

Ms Strettles—Absolutely. And that is fine. Some people will be managed really well in a nursing home because it has the infrastructure that is required by that person and the location is close to their family. If there were clusters then there would be expertise, and that would resolve some of the issues that we found in looking at the problems of people living in nursing homes. However, nursing homes are not always the answer. For people who are going to live an ordinary life span, a nursing home is not the best model of care, so I also think that looking at community living arrangements is really important. Two of the people in my study went into an alternative supported accommodation arrangement. One person went directly from rehabilitation and one person went from a nursing home. That is not available in New South Wales—you cannot make that transition. That continuum from a rehabilitation-enabling focus to helping someone to move on with their life is lost when people go to nursing homes, because they are different structures. I think having a continuum is really important, as is having choices and being able to live maybe by yourself or with one other person in a small cluster, instead of in a nursing home. Nursing homes generally have around 40, I think, in the smaller ones.

Senator LEES—So you have nothing in New South Wales specifically. The unit that we saw in Perth was basically a double home. In the normal run of events it would be two units connected by a little module that could have been a car park but it was, I think, where the care attendants stayed overnight. You have nothing like that in New South Wales?

Dr Hodgkinson—We have looked within Western Australia, Victoria, Queensland and the ACT. New South Wales, which has the largest population, has nothing. Everything that Barbara has said is quite true. One of the real distinguishers is the choice of the family. These are young people who have had a catastrophic injury and whose parents are really committed to the long-term care and provision of those things. So they are not really accepting any form of care outside the family home and yet, if you consider the hours of care they are putting in, the cost of a nursing home bed can be easily put towards that care. Three and a half hours of care a week is very cheap, and that is all that state is putting towards care whereas the Commonwealth would put much more towards a nursing home bed.

The other thing to consider is the hours of care. We often think nursing home care is 24 hour a day care. Barbara has looked at the different care needs of these people and certainly in a less institutionalised environment where they are supported, we can reduce that care right back to 16, eight, or maybe even only six hours a day so that the actual cost to care for those people can be less in a community environment that is appropriate and fosters non-institutional behaviour than in an institution.

Senator LEES—My last question, because I know there are other senators wanting to ask questions, is: an option that was put to us—I am not quite sure which hearing it was at; it could have been Adelaide—was a model that is being looked at now for age care overseas, particularly in Canada, may be applicable. I am asking whether it would be applicable for you. It is an extended day care option where five days a week the person—it might be an aged person or someone with acquired brain injury—is collected by bus at, say, 8.30 in the morning and they return at 5.30-6.00 at night. During the day there is a specific program. In some cases, I guess, it would have to include rehabilitation but it would be with people who are also in their particular category. Is that something that you have ever looked at?

Dr Hodgkinson—The first priority for people is accommodation and support of accommodation. The next one, running almost immediately after that, is what they do with their time. It needs to be appropriate and tailored to the needs of a traumatic brain injury patient. If you sustain your injury at 25 when you have already worked for five years as an apprentice carpenter, you have skills and abilities. You may not have a memory anymore or fit well into a work situation; nevertheless, you have something that you can offer and understand. You do not necessarily fit well into what used to be called a supportive workshop environment where you are surrounded by people with other life experiences.

Prof. Barton—We do have some types of respite care in the palliative care setting. Again, there are a broad range of people who are involved. Most cancer patients are over the age of 65, so there is the same question of abilities, particularly with some of the problems of brain tumour patients, and finding appropriate facilities for them is quite difficult. Entry into respite care is usually limited to one or two days a week but there are some services like that available. They do not get over the issue of trying to keep people at home when there are lifting problems, problems with continence or when they need a special bed. Those are the main problems, the main reasons why people end up in nursing homes.

Senator McLUCAS—Could you explain a little more about the ComPacks program. Is that a state government program?

Mrs Langford—It is a state government program. I think it started 12 months ago. It was piloted at our hospital and at Liverpool Hospital. We are linked in with the local community option service—Centacare, in our case—and they assess a patient either in hospital or once they get home. It is immediately on discharge; we can pretty much guarantee that people will get the care they are requesting on discharge for up to 10 hours a week. They need to require two services—for example, personal care and shopping or transport. It is a brokerage system through the local Community Options Program, COP. It was rolled out to most other hospitals across New South Wales and has been quite well received. The problem we now have is that they have had to cap how many packages per week they can give, but it has not been too bad at the end of the day. There is a maximum of six weeks. We are finding that a lot of people may need services, case management or home care after that six-week point. That is where it falls down again.

Senator McLUCAS—Professor Barton, you explained that the longevity of someone from diagnosis is approximately two years. Is it a fairly predictable health track for those people?

Prof. Barton—No, unfortunately it is very unpredictable. There are quite a lot of fluctuations, depending on their medication. Some people develop major problems with fitting, with epilepsy, which means that they cannot drive. All people with brain tumours are not allowed to drive, so that is an immediate disability for them. One of the major problems with trying to get them in for radiation treatment, which is one of the most effective treatments, is that it is given every day from Monday to Friday for six weeks, so getting people backwards and forwards if they cannot drive can be difficult. A lot of people, certainly in the older age groups, have wives who have never driven, so that is another limitation.

Often people stabilise for many months and then they may progress again. Sometimes we get some reasonable short-term improvements with chemotherapy or reintroducing steroids. Steroids in particular have a lot of side effects and affect people’s mobility. Even at that point where someone is disabled and unable to look after themself, they often still have several months to live. That is really at the very hard point of getting them extra care. Prior to that we can often help with respite care and some other services, but once they reach that point, which is usually two or three months before they die, they are really in need of much more intensive care and supervision, particularly supervision. You can have people who are physically quite fit but cognitively very disabled and quite dangerous to themselves and often to the people around them.

Senator McLUCAS—I think it is hard to make a generalisation from what you have just said, but what in your view would be the preferred care arrangement, if everything that was desired was available? I dare say some families would want at-home care and some would like alternatives.

Prof. Barton—Most people want to stay at home, but not everybody. The best care is flexible care that allows people to have some options. You cannot get one package that fits everybody. There certainly needs to be much better access to the facilities that are available for aged care. I think that probably applies across the board, both in nursing homes and in the home care services. That is really what we have recommended in our submission. It is just a broadening of the categories and perhaps some further investigation or extension of some of the available services like the ComPacks program. For instance, the PADP, which is the service that supplies prosthesis equipment, will not support these people at all, because they are too young.

Senator McLUCAS—Is it simply because they are too young?

Mrs Simpson—PADP only have limited equipment, so for a person who is bed bound and wants to go home to be cared for by their family we will usually get the occupational therapist to be involved. Usually, the family have to pay the cost to hire a hospital bed. If the person cannot transfer themself they will need a hoist, and all that equipment requires a hire fee. I have a set of costs here from the cheapest company we can find: all this equipment will cost a family $180 per week. They also have to pay the delivery fee, which is $200 for the deposit and $75 for the delivery. Most of these families are on a pension. They have probably lost income because they have had to give up work to care for a person with a brain tumour. It is just a very difficult situation for them.

Prof. Barton—You have to have those facilities before you can get some of the nursing in the home. You have to shell out from your own pocket before you qualify for the extra support services.

Mrs Langford—And that is due to the OH&S risks for workers that come into the house.

Senator McLUCAS—It is almost a catch-22 situation: if you have not got the money you cannot get the service. Ms Strettles, you were talking about a cluster. Can you describe what that physically means in a nursing home?

Ms Strettles—In a nursing home it is not going to the extent of redesigning; it is saying that you will have maybe half a dozen or 10 residents with an acquired brain injury. Then you resource that small group in a different way than you do the rest of your population. Unless the organisation itself puts aside money, it does not come with any extra submissions or grants or anything like that to change the way in which those services are provided. It is done internally or through your own organisation or management structure. Does that make sense?

Senator McLUCAS—I am trying to visualise it. Might it be a wing of a larger nursing home that is put aside for people with acquired brain injury?

Ms Strettles—Yes.

Dr Hodgkinson—It is where the prevailing music can be for younger people—where they may go out in their wheelchairs to some outing that is more of interest to a young person. They might go and see a football game or something like that, which is not appropriate for or desired by the elderly. So, young people do not have to join in to bingo and they do not have to listen to old-time music.

Senator McLUCAS—Those cultural things are such an issue, aren’t they?

Dr Hodgkinson—The age gap between a 25-year-old and an 85-year-old is many years. It is two generations.

Mrs Langford—That is one of the problems you find in nursing homes of young people who are in a palliative phase. Sometimes they want privacy to be with their loved ones—you are talking about four-bed and two-bed nursing home rooms with old people who want to go to sleep and people wanting to be there for their last moments—and the facilities just do not cater for that. There is not a lot of room for personal mementos. That is why their choice is such an important part of things—letting them remain at home, if they choose, in their own bed. It is those very simple things.

Dr Hodgkinson—One of the other issues is the turnover in the aged care people, because the average length of stay of an aged person in a nursing home, usually in the latter phase of their life, may be two years at the most. Some of our patients complain that the old man in the bed next to them has changed six times and that this is a place for dying—that the old man died again and there is someone new there. It is a very depressing environment for someone who has got maybe another 30 years to live.

Senator McLUCAS—The other issue that you were talking about is the gulf where a person has finished with the health department and then they have to move into the disabilities department. The other part of that, as far as far as I can see, is the Department of Housing. We were in Western Australia and they are so creative over there. They seem to have the Department of Housing, the department of disabilities and the Department of Health talking to each other. Some of the solutions have been quite fantastic. The other thing that I find interesting is that it is really not that expensive. It is renovation of old public housing and being a bit clever about how you can use the pension. A person may have to part-pay the accommodation, with that then topped up with some disability support funds, and then just accept the services coming out of Health. It is not that hard.

Dr Hodgkinson—The issue we have is not with housing.

Ms Strettles—That is right. It is the support. We just cannot get the paid support that is required for people to live in the community.

Senator McLUCAS—What sorts of housing models have you been able to talk to the Department of Housing about?

Dr Hodgkinson—Perhaps it would be where someone is fortunate enough to have their own house. Can you think of a situation where we have worked with Housing, Barbara?

Ms Strettles—On an individual basis we can apply to the housing department and the housing department can modify houses and do those kinds of things. Generally we would have more experience, or success, with insurance companies being able to approve extensions or modifications to a house so people can actually build a new wing, including carer’s accommodation, onto the family home for the person with the injury. Those are the kinds of things that are in place. We have had some talks with the Department of Housing. The Department of Housing is really good at accommodation, building services and things. We have also spoken to people like the Lions Club, who were very interested in getting a property and then being able to renovate it and using their local resources to do that. Those discussions can only go so far when you cannot actually guarantee that the person that is moving into the house will have the support. Those are the kinds of problems that we have had.

We had a submission where the Department of Housing were willing to build a purpose-built centre but the blockage was in getting the carer support. There have been quite a few models where the person provides some of their income towards the running of the house but it does not actually cover the cost of their care if they do not have separate funding agreements for those things. The accommodation service in New South Wales, Wareemba Community Living, does have clients living in the community and is supporting them. A small number of their clients do have government funding, but it is usually only a very small number of hours per day that they use over the week. Most of their other clients are from compensation. Compensation in New South Wales assists to break down those barriers because you do not actually have to go through the government departments to come up with what you want. You can look at your staffing issues, your accommodation issues and your support issues. They are the kinds of things that you can develop models for. Most of the people in New South Wales still live with family or live alone. There are not a lot of co-location models for people with ABI and it is because there is no infrastructure and no government support for those models.

Senator KNOWLES—One of our submissions—from the people I think we will be hearing from next—includes a ‘proposed facility profile’, which lists a 20-bed purpose-built unit; treatment rooms and gym; offices for allied and specialist services; a day care unit; bus and car access for community and visitor access; and activity rooms for recreational activities. Then there are the staffing ratios and everything else. It is a very helpful suggestion. Naturally enough I will explore it a little bit more with them when they appear before us, but I would like to hear about your attitude to that type of profile. On the surface it sounds fantastic, but I see difficulties. One of the major difficulties would be a facility that is located there when people are being drawn from here, here and here. What are your views on that?

Dr Hodgkinson—The first choice when people are faced with choosing a nursing home is location. I have known families that will accept a less attractive nursing home because the daughter can visit on the way home from school. That, to them, is more important than a really superb unit. That is the one Carrington is supplying. It is remote and yet it does have a role. There are people who would be very suitable for that sort of thing. I think Carrington is one that has gone out of its way to try and meet the needs of young people. But it is in one area and it is not accessible. We serve the great south-western area of Sydney, including the St George and Sutherland area, so if your family lives in the Sutherland area you are not going to travel to Camden.

Senator KNOWLES—If someone is from Pymble or wherever, it is inappropriate.

Dr Hodgkinson—Yes.

Prof. Barton—We know this from cancer services that have a single Taj Mahal. It is great if you live near it, but it denies access to a lot of people. I think you will see the cancer services in, say, Victoria have gone from that centralised model to a very decentralised model—probably the most decentralised in the country—because of that fact. The same thing would apply for other major specialist services. They do act as a focus for training and education of staff and also for research and development. So I think they have a role, but it is not the complete story.

Mrs Langford—One of important things that was mentioned in that submission was allied health rooms. That is really important for what we are looking at. Teresa recently spoke to a relative whose mother died of a brain tumour in a nursing home. Her swallowing needs, her need for speech pathology, changed in a matter of days. The relative came in to find her mum with a mouthful of food. We do not know how long she had been there like that, because yesterday she could swallow and the next day she could not. That is the sort of fluctuation that can happen with people with brain tumours. They did not have that regular review of equipment needs, swallowing needs, physiotherapy needs. So the allied health element is fantastic and a really important part of things.

Senator KNOWLES—It is a very important part of things. In Carrington's submission they also provide a very useful breakdown of the time required to care for someone, compared to an older person. That is why I was interested to get your feedback on that, as well. Thank you.

Senator MOORE—Whose job is it to sort out this process of who could do what and when? I am constantly getting my head around the services that are provided in a fragmented way at so many levels. If someone in your family has had a traumatic experience, whose job is it to actually lay out the smorgasbord of things to help with their care?

Mrs Langford—In an acute facility it would probably be the social worker.

Senator MOORE—In neither of your cases is it often acute.

Dr Hodgkinson—We call it acute. If someone has been with us for six months or 12 months, they are still in an acute rehabilitation phase. It is not six days. It is at the point of discharge. The social worker will try and guide the family through the multitude of submissions and letter-writing. There is the PADP organisation. There may be Home Care. Then there is Community Options, who could top that up. There may be home modifications applications and Department of Housing applications. Then there are any extra packages that may be applied for as well.

Senator MOORE—Do they apply for each of those themselves, individually?

Prof. Barton—They will get some assistance. It shows you how difficult it is that we employ two people to deal with this. As part of my exercise for medical students, I give them some of the Commonwealth forms to fill in and see how well they do.

Senator McLUCAS—How do they go?

Prof. Barton—Not well. I do not think I do it well, after many years. It is a very arbitrary process to try to make it clear what the person's needs are to fit in the little box. We get surprising knock-backs and we get some things through surprisingly. It is an impenetrable beast. I am very glad we have people who are trained in its management.

Mrs Langford—It is really difficult for us, so it has to be twice or three times more difficult for families trying to understand this. I think there is a lot of time-wasting in our jobs, for the simple fact that we are making numerous phone calls with no success. You have to try all the same phone calls again because next time you might be lucky. I think it is a huge waste.

Ms Strettles—And in the brain injury program, too. We have a statewide program and each of those units have community teams, so there is an ongoing process of case management or social work. Not only is it about the initial discharge planning but it is also the follow-up and maintenance of those things. You might try this program today, for example, but then you might also find out about something else and try that as well. We guide the family through those processes and try to get them to make their own decisions about those things, but we try to enable them to follow through those government processes.

Senator MOORE—Is it getting any simpler? You have all been in the field for a while.

Ms Strettles—No. In fact, it is getting harder. For us, anyway, it is now harder to actually get ACAT approval for people. When there are no options except family, we have found that either families are really willing to do it no matter what the cost and no matter what they have to do and no matter what level of resources they get or families would like other options but reject nursing homes. Then you have the people who actually have no other options so nursing homes are the only option. It is now getting harder to get those people into nursing homes because they are inappropriate.

Ms Langford—Because the aged care package and the nursing homes are limited, the aged care people—the geriatricians and what have you—are understandably looking after their own patch of grass and making it tough for us to refer people to those services. The other thing that Teresa and I often face as socials workers is that families will call us as the situation changes at home because they do not know where else to go or what service to use. That would definitely be the case with ABI as well. It is not a matter of once they leave Health that is it. They are often coming back.

Senator MOORE—Are there enough social workers in this field?

Ms Langford—Probably not. It is not necessarily just social workers either. We become more like case managers.

Senator MOORE—It is in focus.

Ms Langford—We are sort of pulling everyone together. On the acute ward where I work, I am making sure that the OT has done this, the physio has done that and everything is covered and that the family, the doctor and everyone else are informed. I cover neurosurgery, so brain tumour treatment is just one part of the acute management of the brain injured patients and all the people who come in as well. I know we are often arguing very strongly with the geriatricians that someone who is 55 might be eligible for a community package, because that is long-term assistance for 10 hours a week, or the extended aged care at home—that nursing home equivalent—and we are trying to get those people there.

Prof. Barton—We are all covered by the geriatricians. They are the gatekeepers to all of these services, no matter what age the person is. They are the people we have to call in to get anybody into a nursing home.

Senator MOORE—And there are very few geriatricians, I believe.

Prof. Barton—That is right, and there are lots of demands on them.

Dr Hodgkinson—If we batter them around the heads, they will accept this!

CHAIR—Unfortunately I am going to have to wind it up there. That is unfortunate because I think we have certainly enjoyed your contribution and found it very valuable. Thank you all.

Proceedings suspended from 10.38 a.m. to 10.50 a.m.

PENNEY, Mrs Stephanie, Director, Carrington Centennial Trust

RICHARDS, Mr Raad Terence, Chief Executive Officer, Carrington Centennial Trust

SQUIRES, Ms Barbara, Director, Centre on Ageing, The Benevolent Society

CHAIR—Welcome. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if such evidence is considered by you to be of a confidential nature. Witnesses are reminded that the evidence given to the committee is protected by parliamentary privilege and that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee has before it your submissions, and I now invite you to make an opening statement to be followed by questions from the committee.

Mr Richards—I would like to make an opening statement to the committee on behalf of the Carrington Centennial Trust's board and management. Before I proceed with my opening statement, I want to mention some background information in relation to where we have been. I am just following up on your questions to my colleagues from Liverpool Health Service who gave evidence prior to us. A number of meetings have taken place with various Commonwealth and state ministers of recent times, including Kevin Andrews and Julie Bishop. I have also written to the Treasurer, Peter Costello, as a result of his interview with the *Bulletin* magazine following the last federal election. He singled out the young disabled people accommodated in aged care facilities. I picked up on that particular statement and wrote to him. We have also made representations to state ministers for ageing and disability, including their senior officers here in New South Wales. We come from that sort of background and that has been going on for at least the past year. I have been the CEO of Carrington for 12 or 13 months now and I have done that from day one. That sort of process also started some six or eight months prior to my commencement with Carrington in February 2004. We come from that background.

Thank you for the opportunity to appear before the committee and make this statement. As I indicated in our submission, it is mainly addressing terms of reference (c), which is the appropriateness of young people with disabilities being accommodated in residential care facilities. Carrington is a leading aged care provider in the Macarthur region within south-west Sydney. We offer our service through a three-tier system: a self-care retirement village, low care facilities such as hostels and high care facilities such as a nursing home. As the committee would be aware, there are more than 6,000 young Australians with high care needs who have been placed in aged care facilities because there is no alternative providing the required level of nursing care. Young people take scarce aged care beds and preclude older Australians waiting for a bed in aged care facilities. I believe some 2½ thousand older Australians are forced to live in acute-care hospital beds that cost state budgets in excess of $350 million annually.

At Carrington we currently care for nine younger people with disabilities; they are being accommodated in the high care facility. Their ages range from 31 to 60 years of age. Five of these residents came to our facilities when they were in their mid to late 20s. The care requirements for younger people with disabilities, particularly those with acquired brain injury, are more intensive than those required for the frail aged. The younger disabled come to our facilities from brain injury units after suffering a brain injury, often followed by a series of complications. Only two years ago, when I was the general manager of Liverpool Health Service, when Dr Hodgkinson had to transfer some of the patients from her facility, I had to intervene with Carrington so we could transfer those two particular patients from acute care to that sort of setting so someone could care for them.

These particular patients, when they come to our facility, usually have the following characteristics: they cannot move any part of their body; they do not have unassisted sitting balance; they have limited communication; they are reliant on fluid maintenance and nutrition via artificial-tube feeding; and they are fully dependent for all their daily activities, including bathing, dressing and total patient care. After a few years of intensive care given to the younger disabled, today they can sit and move in a wheelchair, they can access programs run by Disability Services Australia and they have responded well to the intensive physiotherapy, occupation therapy and speech pathology.

Whilst we believe that Carrington is giving and will continue to give excellent care to both the frail elderly and young residents, the downside of this is that care is being delivered at huge expense. The funding that we receive for younger residents is based on the resident classification scale funding, the infamous RCS. The instrument is designed to assess and measure the needs of the frail elderly and not those of younger persons. The RCS is in fact designed to measure the multiple pathologies of elderly people—basically lots of little problems associated with ageing, where you can claim in every question as part of the RCS. It does not, however, capture the care needs of younger people who have major deficits in particular areas.

The government has in the past few years implemented a review of the RCS and I believe there is another review currently being undertaken, being addressed as a result of the Hogan report. The review does not intend to address any inadequacies that the instrument may have in capturing the care needs of younger people in nursing homes. All the hard work that we have put into the care of our younger disabled residents has been rewarded by a drop in our RCS categories for those people. In that regard, the RCS is very deficient.

Even though most of our young disabled have an acquired brain injury with some frontal lobe damage, they do have insight and impulse control. They are not disinhibited nor do they have behavioural problems. No claim can be made on any of the behavioural questions of the RCS where the potential maximum score is in excess of 20 points, as is often the case for the average nursing home resident. The areas of greatest need for these residents today to improve their quality of life are physiotherapy, diversional therapy, occupational therapy and speech pathology.

The maximum claim for these therapies is in item D in question 19 of the RCS categories, titled ‘Therapy’. It attracts a weight of seven if more than 30 minutes are provided three times a week. Most of the younger disabled have two hours of therapy four times per week in the physio department that we provide in our facilities. They have a daily passive range of movement exercises attended by nursing staff. They also have speech therapy each day, as per the plan devised by the speech therapist, which equates to some 16.6 hours per week. These therapies are crucial for them to have any chance of improving their condition and preventing the complications that could develop if they were only given the maximum fundable time of 30 minutes three times per week.

Question 15 of the RCS is titled ‘Social and human needs—care recipient’. An item D claim allows for one-to-one activity with the care recipient each day for 30 minutes. Our residents need and get much more than 30 minutes daily. To organise their daily life—listen to their own music, play with their computers, et cetera—the maximum score that an item D claim in this question attracts is 3.01. Like the physiotherapy, they have more than double the allocated time, and there is no way to claim these interventions or time spent with the residents.

Question 16 of the RCS relates to the support given to the family of a resident. Our staff spend far more time on the phone and in person with younger residents’ families members and friends—counselling, supporting, et cetera—than would be expected for an item D claim, and a grand total of 0.91 is scored. That is for the frail elderly. An observational study undertaken by our staff indicated that each of the younger disabled residents would require between eight and 10 hours of direct care daily. This is significantly higher than the 5.1 hours of nursing care that we would provide, on average, to a category 1 frail aged resident.

Currently we have nine or 10 younger disabled people in our facilities, and for Carrington it has become a question of balancing moral issues and financial pressures. As an organisation we have been actively lobbying governments, and our local federal and state members have visited our facilities and met with our younger residents. The Carrington board has made a commitment to provide a parcel of land to build a specific facility to accommodate younger people requiring the equivalent of nursing home care, but of course we require capital funding. However, the recurrent funding responsibility for services for younger people with a disability is defined in the Commonwealth-state disability agreement, the CSDA. The CSDA in each state defines the services to be provided by each party.

Whilst the Commonwealth has primary responsibility for disability employment services, advocacy and research, the state government has responsibility for accommodation services as well as therapy, recreation and equipment. The CSDA is the instrument that governs the funding of all disability services. For alternative accommodation places to be developed for younger people, they must be done under the auspices of the CSDA by the state governments; however, aged care facilities are not part of the CSDA and therefore young people in these facilities cannot access services available to others with disabilities. They are caught in this bureaucratic and political funding trap. Our stumbling block has been: who will provide the ongoing recurrent funding for the operation of such a facility?

Federal and state governments continue to play pass the parcel as far as we are concerned—given the information I gave you earlier—with the belief that if they ignore it for long enough it will just go away. I can assure the committee that the younger people we are caring for will not be going anywhere for a long time, as they are healthy and have long life expectancies. It is, therefore, our collective responsibility to do something to improve the quality of life of these people.

CHAIR—Thank you, Mr Richards. Ms Squires, would you like to make an opening statement?

Ms Squires—Yes, thank you. The Benevolent Society’s submission is already before you. I would just like to draw your attention to two areas that we have highlighted. The Benevolent Society has been around for nearly 200 years, so it has a depth of experience in all sorts of work.

Supporting older people is the major part of our work in the Sydney metropolitan area, but we have always focused on those in greatest need, so our greatest focus is on people with dementia—particularly those with disturbed behaviour.

Interestingly, what we have drawn attention to in our submission is that, for us, the RCS funding tool works quite well in that our residents score very highly. Our dilemma is that, even with the maximum funding available under the RCS, it is still not enough to cope with people with very disturbed behaviour. That is the first part of our submission. The second part draws attention to the community support area. The Benevolent Society is a major player in community support of older people. We now support many more people in their own homes than we do in our six residential aged care facilities.

One of the dilemmas of being a community support provider is that the work is almost invisible. You cannot drive somebody past and show them a building and walk them around because the work is going on in people's homes. It is very hard to get across to people the complexity and the extent of the work because, by its nature, it is almost invisible—which is as it should be. We particularly want to draw attention to our frustrations with the Home and Community Care program as it is administered in New South Wales and the inadequacy of the funding and the Byzantine complexities that are involved.

We did draw attention to one particular program, the Homeshare program, which was highly innovative. Since that submission was put in, we have lost the funding for that program. Part of the reason for that was that the evidence shows that the Homeshare program was highly effective in keeping people from more extensive levels of care but, unfortunately for us, only about an estimated 30 per cent of the money is being saved from DADHC from the HACC budget. Possibly the other 70 per cent is being saved from the Commonwealth's budget in terms of residential aged care. For that reason, it appears that, not surprisingly, we are not getting any HACC funding any longer for that program. We have been told by Warwick Bruen that there is no particular money available to support a program like this. We are faced with 15 weeks to wind it down. I am hoping that another not-for-profit provider may take it over and provide the funding for it, but the Benevolent Society is already carrying a significant deficit, partly because of things like the Eric Callaway nursing home.

We cannot afford to fund the program ourselves, so we are facing this terribly sad task for a program that is highly innovative. Everybody intuitively has said what a fabulous idea it is, but we cannot continue it. We have nowhere to go in terms of the funding other than starting a very long path of political lobbying for some sort of funding stream that has a label stuck on it saying, 'This is for Homeshare.' Without a label we have no access to any particular form of funding for something that is as innovative as that. It is highly frustrating when you can see a program that is working and cannot find the sources of funding for it.

I have again checked the problems in the HACC area this morning with one of our managers who is on the ground day to day. They are now starting to provide domestic assistance, which is about an hour and a half a fortnight of house cleaning and shopping. It is a very effective form of helping to keep people in their own homes longer. They are now able to clear their waiting list from 2003. They are finding that about 50 per cent of the people on that waiting list are still there, have not got service and are very grateful to finally get it. The 2004 people are going to be a little bit luckier because, as funding often happens in a stepwise progression, another organisation in the area has got new funding, so those people will be able to be referred there. But what we will see is those waiting lists beginning to build up again. It is not uncommon for people to have to wait 18 months for even a simple hour and a half a fortnight where all the evidence is that that is highly effective. The HACC program is a constant source of frustration.

On a positive note, perhaps I could end by saying how delighted we are to be a major provider of Commonwealth community aged care packages. There is flexibility in the programs and simplicity in the funding model, where, I am sure you are aware, a certain dollar amount per person per day is allocated by the provider—although I note from previous evidence that the expectation of the ACAT social workers was 10 hours a week. The reality is that we have to average, over our entire caseload, about six hours per week, so if some people can do with a little less we can carry a few people at 10 hours, but we certainly cannot carry terribly many at 10 hours a week. The Community Aged Care Package program is now moving into the Extended Aged Care at Home. The EACH package is a program that we believe is excellent for providing that support for people at home. Its flexibility and lack of red tape is a constant delight to us. I will finish on that positive note.

Senator KNOWLES—Mr Richards, obviously you are most concerned about the RCS and that it does not fit your needs. Aren't you, in all practicality, a square peg trying to fit into a round hole?

Mr Richards—No, because when you look at people with acquired brain injury and other disabilities being discharged from acute care facilities, there is nowhere for them to go. There is no provision of services. These people—and I have highlighted the case of one of our residents in my submission—require very intensive care subsequent to their acute care admission.

Senator KNOWLES—I do not disagree with any of that. Ideally, they should not be in a nursing home facility, so you are trying to fit within an RCS form where they should not be put in the first place.

Mr Richards—Yes, you are quite right. With my colleagues in the previous session, you talked about the need for special funding for people like that. I will highlight to you the costs for one of these people—and we did these figures yesterday. It costs us $98,000 in round figures to provide direct care—that is, only direct care to any of these younger people with disabilities—as against the top person as a frail aged under RCS category 1, which gives you $45,000.

Senator KNOWLES—You are trying to squeeze into a shoe that is not made for you, and we have to look at the other options. I know you were here for the previous witnesses. I am not sure whether you were here for the first witness but I was asking there about how people can get through the state support system and whether we can get information on this and where you, for example, have put in submissions to the state and what the response has been. As you identified in your oral submission, it is the primary responsibility of the state to look after the disabled in accommodation purposes. What have you done in that sense that you could provide to the committee so we could have a look at where things are going and what responses you have received?

Mr Richards—I could provide the committee with our submission to DADHC and talk about discussions with ageing and disability in New South Wales, which was along the same lines of our discussions with the federal ministers for ageing. We provided them with the same submission that I have given the committee. We talked with them. They visited our facilities. We highlighted to them how we can deal with that particular issue and not have such people accommodated in a nursing home but in a purpose-built place. We are suggesting 10 to 20 beds. We have the parcel of land. I invited the department of ageing and disability in this state to sit down with our people and, as a working group, come up with the best alternative solution. One of the issues they highlighted to me is that the Disability Services Act in New South Wales does not allow for such people to be accommodated in an institution; they have to be out in the community.

These people do not fit the community categories that you are talking about because they need intensive therapy. We are suggesting to ageing and disability in this state to look at alternative accommodation albeit within the same precinct of our facilities but separate from the nursing home. I would like to extend my invitation to the members of this committee to visit our facilities and talk to some of these younger disabled people that we care for and also have a look at what we are trying to do in terms of care provision but also at what we are suggesting to both the state and the Commonwealth, which is to establish a separate facility of, say, two or three pods, each pod with four or five rooms, that becomes similar to any community accommodation.

Senator KNOWLES—What response have you had from the states?

Mr Richards—It is the same response. The Commonwealth tells me this is the state’s responsibility. The state tells me that the state act does not allow for this. The state act for disabilities is the most unwieldy act in terms of complication. It is one of those acts that are totally inflexible.

Senator KNOWLES—In what sense?

Mr Richards—There is no deviation from what is written in the act. They have prescribed the model of care, and no-one would be able to deviate from that.

Senator KNOWLES—In other words, they have to live in the community and not in an institution?

Mr Richards—Absolutely. All we are saying is that the institution here is only a word being used loosely. What we are saying is that it is a purpose-built building somewhere in the grounds of our facilities.

Senator KNOWLES—Have you done any work—obviously you have prior to coming up with this model—that you could provide to us showing a comparison between what it would cost to keep someone in the community with the level of care that you provide and what you do in fact provide—if the care was available in the first instance?

Mr Richards—I am just trying to think whether such a comparison is available. As I said, the only comparison I could provide you with is how we care for one of these people and how much it costs us as against someone who is an elderly resident. I am not sure how much it costs to provide services out there. The reason I believe that is not available is that the people we are talking about would not be able to be accommodated out there in the community. They need very intensive care.

Senator KNOWLES—But they probably would not be able to access the level of care that you are talking about anyway?

Mr Richards—Absolutely.

Senator KNOWLES—That is the crux of the issue, isn't it?

Mr Richards—You are quite right.

Senator KNOWLES—Ms Squires, can I just ask one very quick question about your perspective. Keeping people in a home is obviously desirable, but you talk about the lack of HACC funding. There should be other models that people should be able to look at for keeping people out of nursing homes or out of supported care but providing the basics of shopping, heavy washing and things of that nature. Have you looked at the Village Life option?

Ms Squires—I am familiar with it. This is the option of the congregate care and the married couple who provide the meals and so forth? There is nothing about that model that attracts me one little bit. It seems to me that it combines the worst of all worlds. It is not really people's homes and it does not give the continuity of care. Once their needs are greater than can be provided in a very minimal way, my understanding is that that particular model has a reputation for discharge by ambulance—that as soon as somebody becomes a bit difficult or needs a bit of help it is beyond that particular facility and the people will not be profitable, to put it bluntly. I think it has a very limited space and life.

Senator KNOWLES—I am not sure that we are talking about the same thing.

Ms Squires—I am not sure that we are either.

Senator KNOWLES—It is like a retirement village where people can go if they are on a pension. They have their own place; they can access three meals a day; they get their heavy washing done; they can get shopping done and things like that if they need to. It does not have any care rating as such.

Ms Squires—That is right.

Senator KNOWLES—But it has 24-hour call buttons if people need assistance at some stage.

Ms Squires—We are talking about the same thing. A lot of the difficulties that a very frail elderly person will have will be progressive, particularly if they have a dementia. That model is not going to be able to provide care for them for very long.

Senator KNOWLES—I would not think it would be desired for dementia, to start with.

Ms Squires—No, it would not, but it is not always apparent that people are going to develop a dementia when somebody moves into a situation like that. As a dementia develops, with the 24-

hour call button, I am sure that the married couple is going to find that that is wearing very thin if somebody is going to be calling them. I think it has a very limited place. It is not a model that I think is a particularly good one.

The Benevolent Society is doing a lot of exploration around an alternative model called Apartments for Life, where an apartment is adaptable in a retirement village setting under the legislation. By clustering the services and providing them on a community care model, the commitment is that, where a person is motivated and probably able to some degree to top up the services through either family or friends or making some extra payment, that person will be able to stay in their apartment until the end of their life. This model works beautifully in Rotterdam in Holland. We have done a lot of work in terms of its applicability in the Australian context and we believe that, with our vast experience in community care, we can make it work on a community care model, especially with the EACH package becoming available. It is quite a different model.

Senator McLUCAS—I want to pursue that idea of Apartments for Life. What are the financial arrangements? How can the Benevolent Society contemplate establishing something like that? Where is the ongoing capital coming from?

Ms Squires—The financial modelling that we have done would mean building such an apartment block on land that we already own under the Retirement Villages Act of New South Wales. So the apartments would require an entry payment and, depending on the part of the city, that would be the capital contribution plus the deferred management fees and that whole structure. But the model that we are looking at would not have care staff in the building. We would have hotel site staff such as a concierge, a proper cafe, a bistro, social clubrooms and so forth, but not care staff.

When care was needed it would be brought in on the community care model using either HACC in the early stages or the Community Aged Care Package. Each package would be used as appropriate. The beauty of having people clustered is that you can much more efficiently deliver those services. But it also requires a very strong philosophical commitment to people’s independence and allowing them control over their life. The moment you allow a residential care mentality—and I speak as a res care provider—into a development like that, you have lost it because care staff tend to colonise buildings and the residents become the recipients rather than basically the homeowners. It is a very different philosophical approach and one that a lot of people have trouble getting their heads around.

Senator McLUCAS—Would it have to be purpose built because of the potential renovations that have to happen over time?

Ms Squires—That is right, and it is very important that the apartments are built to adaptable standards. I am not very keen on the term ‘ageing in place’—I think it has become almost meaningless—but an apartment that is adaptable at least allows people to not have to be forced to move out because the doorways are not wide enough, for example.

Senator McLUCAS—You said you do not like the term ‘ageing in place’ because it is meaningless. Why do you say that?

Ms Squires—I do not think there is any common agreement on what it really means, so we get such issues as the village life model referred to as ageing in place, but, if you have a stroke or you develop a dementia where your behaviour is a bit disturbed, you are not going to be ageing in that place. I think the temptation for providers who have a retirement village, a hostel and a nursing home on the one campus is always to move people on.

Senator McLUCAS—To physically relocate them.

Ms Squires—To physically move them on. As a provider you can justify that to yourself as being in the person’s best interests, but it also happens that new accommodation bonds coming in and so forth are also very helpful. In the model that we are proposing we would not allow ourselves that luxury. We would negotiate with the person and, if they were motivated and wanted to stay there until the end of their life, we would work with them to achieve that.

Mr Richards—I need clarification of the type of residents we are talking about here, because I do not want us to talk at cross-purposes and all be pushing different barrows. At the end of the day we need to find the proper solution like the ones I have suggested in my submission to cater for people. I am a bit confused about the type of resident we are talking about.

Ms Squires—I am not talking about the types of residents you are talking about, Mr Richards, but obviously we can never have a one-size-fits-all solution, and that is the dilemma.

CHAIR—The committee does appreciate that.

Senator McLUCAS—At Eric Callaway House you have made a decision to adopt a model that has a concentration of very high need dementia residents. Putting the financial issue aside, is that the right model?

Ms Squires—I would prefer it were otherwise, and I would prefer that we could offer care in much smaller units and clusters, but financially that would be impossible. Under the current financing arrangement there has to be an element of warehousing people—grouping them together for economy. Eric Callaway House has four-bed wards, which we are not particularly thrilled about but it is the best we can manage. To keep it going we have a deficit each year of over $200,000, and that is with four-bed rooms. It is not ideal but it is the best that we can do. The care is still a lot better than can be offered in many other places.

Senator McLUCAS—Would the right model be one where there is a range of RCSs in one institution?

Ms Squires—That is a very difficult issue to grapple with. It depends where you decide to concentrate your efforts. For example, we run another dementia facility that is secure. It has 24 people in single rooms with en suites. It is a beautiful design and it is purpose built but, because of the way the legislation is written, we have to cooperate with the ACATs. When new patients come in they are assessed as low care but, amazingly, fairly soon afterwards they are reassessed as high care. We could not afford to run the facility without the accommodation bonds. Without the high-care level of RCS we could not afford to support those people.

There are 24 in the unit, and we only just manage to support them. When they lose their mobility we have to transfer them to a nursing home. Personally I find that very painful, and so do the families, but we could not continue to provide that level of care. The cost of one extra nurse for a year would absolutely blow us out of the water. That decision is part of the continuum. You make choices and you do the best you can. I do not think there will ever be an ideal solution but, at least, it is important to recognise the limitations and not to pretend.

Senator McLUCAS—With regard to the Community Aged Care Package, were you saying that you make a decision to share the allocation—that, although this is one package, your assessment of the needs of that person is that it is not for the full amount, so you able to stretch that package to service, say, 1¼ or 1½?

Ms Squires—Because the funding model is very simple and very flexible—it is the dollar amount per person per day—the provider is able to pool that money and use it in that way. We have done some innovative things. There was one small group home of seven retired nuns, and we managed to spread two community aged care packages to help support the lot of them. This is where some of the inspiration for the concept of Apartments for Life has come from. You can make more efficient use of those dollars and make them go further for people.

Senator McLUCAS—Is that normal, or is it something that just the Benevolent Society is doing? Do you know whether other providers do that?

Ms Squires—Other providers do that. We probably go a little further than others in that we have a value structure such that we pride ourselves on tackling difficult situations and finding ways around them. So sometimes we make life hard for ourselves. The capacity to use those packages is certainly available within the guidelines. I know there is a Commonwealth person here. I am not sure whether we should have allowed the other nuns to benefit but, if you are doing the shopping for one person, it is no problem to pick up something for someone else. Generally it is not difficult to pool the hours and use that budget quite creatively to get the maximum outputs and achievements for people.

Senator LEES—I would just like to go back to some of the comments Mr Richards made regarding deinstitutionalisation and the state law. I would like to try and work us from where we are now in New South Wales to what is ideal, both in the aged care sector and in particular for young people with disabilities. You are saying that, in order for the state to have a part of specialist, purpose-built facilities for young people with disabilities, we need a legislative change from where we are now?

Mr Richards—That is the indication given to us by various senior people within DADHC in the state.

Senator LEES—So, with the move to deinstitutionalisation back in the late eighties and early nineties, what they meant by an ‘institution’ was a sort of multistorey, multicapacity, huge-sized whatever?

Mr Richards—That is correct.

Senator LEES—Even though we are now talking about modules much like those which many of the more modern nursing homes have, where you can walk into the courtyard and, as we saw in Perth, have six or eight units that all look like individual homes? Does the legislation still catch that?

Mr Richards—From a funding point of view, yes, because the legislation will not recognise those facilities for funding purposes.

Senator LEES—So you cannot have a sort of aggregated community facility—or call it something else?

Mr Richards—Let us put it this way: if tomorrow the Minister for Ageing recognises this under the innovative pool funding, we might put in a submission to say we can build a facility such as I described earlier in my submission. That facility would have, say, three or four pods, where each pod has, say, four separate rooms. It becomes like a home and is separated by corridors et cetera from the next pod. If they say, ‘Here is $3 million; go and build that facility and trial it,’ under that sort of innovative pool funding I will have probably only three or four years of recurrent funding. After that, there is no guarantee, unless the state and the Commonwealth come together and say, ‘We need to recognise this as a separate funding pool for people with disabilities, to be recognised in a model of care like that.’

Senator LEES—Looking at the facility that you have planned, you have the land. If you were able to get, say, 30 of the next aged care beds that the Commonwealth releases for New South Wales, what sort of top-up and guarantees would you need beyond that? Is it roughly double the level of care?

Mr Richards—Absolutely. In the past 12 months, my colleague Dr Hodgkinson, from the previous session, was in touch with me to accommodate three of her patients. I just flatly refused to take them, simply because, similar to our colleague here, I do not want our facilities to go into that sort of debt, where no-one recognises the plight of these people in terms of funding. I cannot fund $98,000 or $100,000 in round numbers to care for a younger disabled person, when I can get someone who is 75 or 78 coming into a nursing home and the level of funding is commensurate with the level of care I am giving. That is the dilemma we are facing. So we stopped at those nine or 10 younger disabled, and hence the ages have changed. They have gone up to 60 now—three of them at least are between 55 and 60. It is problematic.

I do not know what happened to those three people that Dr Hodgkinson requested me to take—I do not know where they went. There needs to be a major change in the funding and recognition of people like that in a model of care like the one that I am suggesting. As I mentioned to the Department of Ageing, Disability and Home Care here in the state, we are quite open to having a working group looking at the best model of care. I am not suggesting that our model of care is the best one or that we cannot deviate from that; it is just that I need to draw people back to the table to start talking about and recognising those issues.

Senator LEES—I have one last question regarding the money that you were looking at raising. What sort of money are you talking about needing for that facility to be built?

Mr Richards—In round numbers as far as capital funding is concerned, maybe $3 million to $4 million. I am just throwing you a number based on a recent building experience we had. That would be for a special facility to accommodate the needs of these people. Once that is built, we need to make sure that recurrent funding is continuing.

Senator LEES—So you would need an aged care funding package from the Commonwealth, if we are looking at joint responsibilities?

Mr Richards—Yes.

Senator LEES—After all, you are freeing up nursing home beds, so that should not be a problem.

Mr Richards—Absolutely, as I highlighted before.

Senator LEES—But you would also need a disability component from the state in the long-term, so that it is an ongoing, guaranteed funding base?

Mr Richards—That is correct.

Senator LEES—They would basically be equivalent—in other words, you would be doubling what a high-care, level 1 nursing home would be?

Mr Richards—Yes. Here we are talking about very high levels of care for people like that.

Senator LEES—If we are actually going to give them the care they need and get some rehabilitation services and appropriate age services, it would be that level?

Mr Richards—Yes.

Senator LEES—Thank you.

Ms Squires—I think both of us are talking in similar terms about outliers—we are talking about people who just do not fit the norm of the system. If you have a bell curve, you have outliers, and these are the ones who are dropping off at the moment for various reasons. They are different ends—they are people with dementia and disturbed behaviour and younger people with brain injury; we have highlighted people with Huntington’s disease, and it is the same with multiple sclerosis. Again, it is the outliers of a system that does not have the flexibility and a system that encourages buck-passing between the Commonwealth and the state, unfortunately.

Senator LEES—We have seen the solutions in WA—we have been to Huntington’s-specific, MS-specific and brain injury specific facilities, all of which from the outside look like just a cluster of houses.

Mr Richards—With that high level of care.

Ms Squires—You could have also gone to a high-level, disturbed dementia behaviour facility in WA, where there is some very good cost sharing between the Commonwealth and the state. WA can do it, but we do not appear to be able to do it in New South Wales.

Senator LEES—I have also seen a high-care dementia facility with special outdoor facilities in Queensland.

Mr Richards—Is the funding for that particular facility shared between the Commonwealth and the state?

Senator LEES—That is our understanding, yes. My problem is that, if you have legislation here that actually prohibits that because it is classed as an institution, we have an interesting issue.

Mr Richards—You do.

CHAIR—Thank you all for your contributions and your submissions to the committee.

[11.38 a.m.]

FLANAGAN, Ms Lynette Anne, Member, Branch Delegate and Branch Secretary, New South Wales Nurses Association

HEATH, Mrs Christina McRae, Member, New South Wales Nurses Association

HOLMES, Mr Brett, General Secretary, New South Wales Nurses Association

McKENNA, Ms Lucille, Councillor and Branch Delegate, New South Wales Nurses Association

CHAIR—Welcome. Do you have anything to add to the capacity in which you are appearing?

Ms McKenna—I am the director of nursing at a 54-bed nursing home in metropolitan Sydney.

Mrs Heath—I am a registered nurse for a retirement village.

Ms Flanagan—I am an assistant in nursing in a nursing home.

CHAIR—The committee prefers evidence to be given in public, but evidence may also be given in camera if such evidence is considered by you to be of a confidential nature. Witnesses are reminded that the evidence given to the committee is protected by parliamentary privilege and that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee has before it your submission. I now invite you to make an opening statement, to be followed by questions from the committee.

Mr Holmes—As you say, the New South Wales Nurses Association submission is in front of the committee. I recommend it to the committee for their attention and hopefully for some action to occur out of it. I will go straight to the point in terms of our recommendations. The Nurses Association has been conducting a campaign over most of the last three years called A Fair Share for Aged Care. Part of that campaign has been about ensuring that there will be adequate numbers of skilled nurses to provide care now and in the future to some of the most important people in our community—the most dependent aged and frail.

During the course of that campaign, we have also gone through the process of making a special wages claim, on behalf of our members, in the Industrial Relations Commission of New South Wales. I believe that during the course of that case we were able to identify a number of issues which are relevant to the inquiry today. They relate to our first recommendation: we believe that legislation should be introduced to ensure that service providers are made to comply with the same accounting standards as listed companies and to prepare general purpose financial statements, and those statements should be filed on the public record.

I am very glad to acknowledge that the federal government and the Minister for Ageing have made a good start by putting in place the conditional adjustment payment program, which has identified $877.8 million in additional funding over four years. Part of the requirements there is to provide information and opportunities for staff about education. We see that as a very important step. We believe that there needs to be concentration on ensuring that there will be a high level of skill provided to the residents of our aged care facilities. As we all know, all of the statistics tell us about the increasing acuity of the problem of residents in aged care and the increasing needs that we face in the future. We believe we need to ensure that there is a work force with appropriate levels of nursing skill to be able to provide that care. We do not believe that it can be done at a cut-rate price for the labour that needs to be provided.

The case that we ran in the commission identified that there will be some resistance to one of the requirements of the CAP program—the provision of audited accounts. The government has not gone far enough in saying that the audited accounts should be available to residents or prospective residents and their relatives. It is not clear what the intention of the government is in saying that those audited accounts will be made available to some body identified by the department for the purposes of financial assessment and statistics gathering. Our experience in the state industrial aged care case was that the employers were very reluctant to supply that information. Indeed, even one of the witnesses provided by the industrial association for the employers came to the industrial commission saying that he did not own his financial accounts—they were owned by his accountant, and that he could produce only a summary provided by his accountant.

We were able to subpoena a number of the financial records of the witnesses who said that they were unable to pay any increase in wages. Those subpoenas were made on a confidential basis and made available only to our counsel and one industrial officer from the association. What also came out in evidence I attended was that strange mistakes are made in the accounting practices of some of the aged care facilities. I hope this is a rare incident, but there was a situation where one witness’s first statement to the bench was: ‘I have to make it clear that I’ve informed my accountant to tell the tax department that there’s been an error over the last three years because my son’s HECS fees for his course in veterinary science have been put into the training budget for the nursing home.’ That was $21,000 worth of HECS fees; in that same period, the nursing home education budget was a bit over $1,000. That provided a level of concern that if these were the witnesses selected by the industrial association for the employers to come forward and prove that they could not pay then I am worried about the employers who did not want to bring their books forward, who were not prepared to have scrutiny.

The government proposal says that these audited accounts—and there is no specification that they meet any particular audit requirements or standards—will be then available to some external body to the department. They will be available to some poor desperate prospective resident who is, in a situation of bed shortages, having difficulty finding somewhere to be accommodated, or the relative of a resident having difficulty finding somewhere to place their mother, father, brother or sister. These people will be in a less than good position to make a full assessment of the audited accounts in front of them and what that really means about how that money is being spent.

One of the other things that the nurses association has been campaigning about is the need to ensure that the money provided by the federal government is actually spent on providing care to residents. In our submission we recognise the history of previous funding models, of the CAM and SAM funding. Whilst we are not proposing a return to the old days, we certainly feel that accountability for the expenditure of funds is an important way of ensuring that there will be staff available to provide the level of care that the residents in our aged care facilities need. I know that my fellow witnesses here can give you first-hand evidence of the needs in those facilities and the need to ensure that the money available is properly spent in providing that care.

We note that the minister has announced that there should be some broadening of the prudential arrangements for accommodation bonds. Our witness in our case, Professor Bob Walker, from the University of New South Wales, identified in the accounts provided under subpoena from the employers that there was an outstanding matter in relation to how those accommodation bonds were recorded and how they formed part of the operating funds of nursing homes. Part of those, by legislation, can be used, but there is very limited control over those prudential arrangements for those accommodation bonds. We welcome the proposal from the minister that that be put in place some time before July this year. We hope that the requirements are such that it makes it a much more transparent situation for people having to pay for accommodation bonds in the low care facilities—so that that money is properly accounted for and used as well.

CHAIR—Mr Holmes, I am just conscious of the time. I know the points you are covering have been well argued and well presented in your submission. I am just wondering if you might just finish up with a conclusion.

Mr Holmes—I would conclude by saying that our proposition to the committee is that, whilst the government has started to recognise some of the issues we have raised, there needs to be a further commitment by the government to improve accountability to ensure that money is provided for the provision of care and that there is a continued effort by the government to increase the amount of funding available to aged care services to ensure that, as the population ages, we have sufficient qualified nurses working in our aged care facilities. I suggest that Ms Flanagan might be able to make some comments.

Ms Flanagan—I am an assistant in nursing in a nursing home in regional New South Wales. I have been there for 22 years. All our residents are high-care residents.

Firstly, I would like to agree with what has been said by other witnesses about our inadequate rates of pay, our high workloads and the fact that we are not paid for the qualifications that we have. Secondly, the aged care sector has real difficulty in recruiting young workers. Most of our staff are in the forties to sixties age bracket. Some are close to retirement; others are seeking less heavy or better paid work. The nursing staff in my facility are employed on a part-time basis. This results in staff leaving to obtain full-time work in other areas or working at two jobs to ensure that they have adequate financial resources. The risk in that is that they can become overtired; they are forced to work double shifts: because they are insecure, they do not turn down a shift; they may not know when their next one is coming.

There is also discontent among assistants in nursing that money received from the last budget has not gone into improving wages for nurses. Although the budget suggested that could be done, it was not mandatory for that money to be used that way. The current method of funding imposes no conditions on how the funding money is to be spent. The staffing level depends on what the proprietor wants to spend on staffing. We feel that funding that is tied to specific areas—such as nursing care—is preferable. We know then that the residents will get the nursing hours they need.

Shortage of skilled staff is also a problem. It places a great burden on the assistants in nursing who are skilled and experienced: you are constantly having to assist others to organise their work and having to deliver on-the-job training. We certainly do not get paid for any training of other staff that we do.

Lastly, since the advent of the accreditation system the amount of documentation has greatly increased and it has become more complex. The paperwork has taken us away from spending time with our residents. In our facility the RCS documentation is completed by assistants in nursing.

Documentation audits that are carried out by the agency and the Department of Health and Ageing are seen by staff as visits to find ways to remove funding from the home. For example, we had one resident who had suffered severe brain damage and was quadriplegic. In spite of his medical diagnosis and his physical condition, we had funding removed because we had not provided through paperwork that this resident was incontinent of urine. We had to prove he could not tell us when he needed to urinate; that he could not let staff know this; that he could not have his bladder retrained and that he could not be successfully toileted by staff. The deputy director of nursing sent off approximately, as I heard it, 20 pages of additional documentation to have that funding restored. Certainly it was a large waste of her time and, for a resident whose condition was never going to change or improve, we feel there needs to be more flexibility so that you are not constantly doing the same paperwork for those residents when there really is no prospect that their funding needs will ever change.

CHAIR—On the paperwork, are you in a position to advise the committee about the sort of paperwork that is necessary? We have this dilemma in that there needs to be a benchmarking process to ensure that there are some standards. How do we actually get to the stage where it can be flexible enough or adaptable enough? There are plenty of nursing homes that are doing the right thing. The concern is that without those proper standards or the amount of paperwork, it will create the opportunity for some nursing homes not to do the right thing. Do you have any feedback for the committee on that as a practitioner?

Ms Flanagan—I can let you know the amount of paperwork that we do. There are 21 questions that have to be answered in the RCS and they cover all aspects of the care—physical and emotional—that we deliver to residents and to their families. When a resident comes in, you begin the RCS within seven days. We have questionnaire sheets on each of the areas which are filled out every day for three weeks by each shift—that is, three times a day. Assessment sheets on various needs have to be filled out. You will have assessment sheets on sleep patterns, bowels, incontinence, and also behaviour sheets on which you record what the problem was, what action you have taken and the success or otherwise of the action you have taken to deal with those problems. Then the daily progress notes also have to be filled out and each resident has to have a progress note filled out once a day. Any time anything different or exceptional happens to a resident, you have to record that. It is expected that, if something exceptional happens on one shift, you would make a note for the following shifts as to whether there was any change in the condition that had occurred before you came on.

The problem, as I said before, is that there are some residents, particularly those in category one which is the highest category, whose physical needs we are not really able to improve if they have had major strokes or have extreme, last stage dementia. Their physical needs are never going to lessen. It just seems that the amount of paperwork that we are doing for those residents may not be necessary because we are not going to be able to achieve greater results. You still need to document things like their skin integrity because if you are not giving that care correctly they are going to end up with pressure sores. However, with things like their mobility, they are not suddenly going to get up and walk. There are areas like that where it could be reduced we feel and that is from our level as assistants in nursing doing the care.

Senator LEES—I want to follow straight on from that and ask about the computerisation of your records and of your processes. Is that happening in your nursing home?

Ms Flanagan—No. We have discussed having laptop computers but that has not happened.

Senator LEES—Can I ask anyone on the panel where that process is up to from your perspective, working with the nurses who are on the front line. What are the limiting factors and the inhibiting problems? Do the nursing home assessors think it is acceptable for you to be managing this work without using computers?

Ms McKenna—I do not know of any nursing home in my area that has a computerised program. We certainly do not in our organisation. Obviously there are some things we do on the computer, like the care plans, but not for the day-to-day—

Senator LEES—Can you see what the problems might be? One of the models that has been put to us—and I have seen one operating in South Australia—shows, basically, all the information on a particular patient. It just comes up again the next day, and the only thing that needs to be done is for any changes to be noted. You do not have to redo every single box if there are only, say, three boxes or three areas out of the 21 or whatever that are going to change.

Ms McKenna—Ongoing progress notes could be done in that way, but not in the assessment period, because under the Aged Care Act there is a requirement that during the assessment period you do these thorough assessments in every aspect of care that the resident needs. So they would be individual. Even if you were doing them on a computer, you would still have to sit down and do them in that way. My nursing home is an older nursing home, built in 1970, so we do not have a lot of space. Most of the information is gathered in case conferences with all the staff and then it is put into the computerised care plan—one person puts it in. But certainly there are models out there were the nurses actually have hand computers and they put things in as they go around.

Senator LEES—Yes, that is what we have seen.

Ms McKenna—I have not actually seen it in action

Senator LEES—Do you think that process is a good idea? Apparently, it saves a lot of paperwork—as far as I am aware; I do not have that in concrete. Is there anything we can recommend to reduce some of the barriers you face and some of the hurdles in implementing that?

Ms Flanagan—When that was discussed as a possibility to be introduced where I work, it did not eventuate, and I think cost was a large part of the reason—purchasing the equipment and training the staff, because, although a lot of people are computer literate, a lot of the assistants in nursing are not and they would have required full training, and it simply did not happen.

CHAIR—I want to go on a bit more about the paperwork related to accreditation. In the submission you say:

> Staff commented that 'the accreditation process is a farce as everything is set up for the day and then disappears'.

Is that the common treatment in nursing homes of the accreditation process—that it is simply something you do to get over the line and then you go back to doing what you were doing until the process starts again?

Ms McKenna—I am sure that is the case. I have heard of cases where that happens. In the nursing home where I work, it is certainly not the case. We have a very grassroots quality program that functions very well and involves all the staff. When the accreditation comes to us there is really no issue. Obviously it is the same as having visitors on any given day—you make sure that your place is tidy and that everything is in order. But there certainly are places where that happens.

One of the most disappointing things, I think, is that, with many of the places that have so-called commendables and merits, that standard is not necessarily reflected in the outcomes. I certainly would not be prepared to put myself up for the extra workload that is required to go for one of those ratings, yet I think I run a very good nursing home which should be able to achieve those sorts of ratings. With the first round of accreditation, a nursing home up the street from me got, I think, 17 commendables and yet, at the time they got those commendables, they had a huge number of staff vacancies. They had a management structure in place which was able to present very well documented and very glossy education programs and things. But if you talk to the staff at the bottom, they were really struggling. Two weeks after accreditation they had 27 vacancies on their staff. So what you get with the accreditation process is not always the truth. It is not always a case of what you see is what you get.

Senator FORSHAW—Just another question in relation to documentation. In your submission on page 7, you state:

> A number of callers to the phone-in stated that they spent their time **documenting care which was never delivered.**

Could you maybe illustrate a bit further what that involved?

Ms McKenna—I had a few words that I was going to say, but I have not actually done that. This is an industry where there are a range of proprietors, and there is a for-profit motive for most people in it, even the charities. I work for a charity. It is run as a business: we are required to make a profit for it to go to other areas outside of aged care. There is certainly very much a push for categories to be pushed up and staff to be pushed down to increase that profit. Ultimately, you will find, various places have set up various ways of documenting care. In places where one person does all the documentation—and that happens in some places—that has to be questionable, because in places where documentation is being done across the board by all of the staff one would hope it would be truthful. But it depends on how people are pressured to get the categories up.

I can tell you that in my organisation we have just had an audit done by the management arm of one of the industry organisations and that audit, which has come back to me and which I just commented on to my CEO, strongly recommended that the categories be pushed up, that we are outside the industry averages and that my staff be pushed down. Of course, I am strongly resisting any change and I do not know what will be the board or the CEO’s final decision. But, at a time when our aged care residents are sicker and frailer, our turnover is greater, our average length of stay is shorter, the needs of the residents are much more complex. There is a recommendation from the industry organisations to do this. To be quite honest, if I had to do what has been proposed, I could not be compliant with the act—there is no way that I could be ensuring the safety of the residents.

Senator McLUCAS—I will pursue that accreditation question further. One of your recommendations is that the accreditation process should be similar to that used to accredit public hospitals. Can you tell me what your rationale for that recommendation is?

Mr Holmes—The association believes that the current process is certainly not reflective of what happens all the time. The public hospital accreditation process is not without its detractors as well, but it utilises a range of industry experts to make their professional assessment of those facilities and provides that accreditation over a number of years. So there are similarities in the process, but the association has more confidence in the ACHS process than in that run by the accreditation agency.

Senator McLUCAS—When you say ‘more confidence’ do you mean that you think it is a more accurate instrument?

Mr Holmes—We believe so. We believe that it is also conducted by people who are still working in the industry and who are released from their substantive positions to undertake that. The agencies, as I understand it, are in a different situation to that, with much larger numbers of facilities to cover.

Ms McKenna—I think that in the public sector these people take a much more realistic view of the situation that the organisation finds itself in. Because we have to be compliant—and compliance is the issue—there is no allowance made for work force problems or for the range of issues that are huge issues for us on a daily basis in providing the right skills mix and the right numbers of skilled staff to do the job. There is a huge reliance on agency staff in our industry—and in certain parts of Sydney it is greater than others—but there is no allowance for those sorts of things. The department and the accreditation agency do not make any allowances for those things. If you cannot get something done because you have not got the right staff on the day, that is not considered, and that is very distressing for the nurses who are trying really hard to do the right thing.

That leads into something else. The nurses are the ones who are bearing the brunt of this system. They have carried this system on their backs for years. They are the ones who go the extra mile, give the extra hours, raise the money and run the raffles. Everything that holds this industry up is done by the nurses. The nurses are the ones who get into trouble when the RCSs go down after there has been an RCS review. It is the nurses who wear the guilt, not the proprietors or the organisations. Then the proprietors say they cannot pay us the same money. We cannot get the staff to work unless we can pay them the same money as the public sector nurses.

I have been a director of nursing for 26 years and I have worked in aged care since 1969, so I know more about aged care than most people. It really distresses me that maybe I am considered a second-class nurse, because I am paid a second-class wage, and yet I consider myself to be an outstandingly good nurse who has given hugely to this industry and chose to work there because there are great rewards for working in aged care. The wonderful long-term relationships you make with your patients and their families, and the difference you make to their lives, is just something that you do not get in the small, short-term, four-day average stay in a public hospital. So many of use choose to work in aged care because the work is wonderful, but we want the recognition.

Mrs Heath—I want to add to what Lucille has said. The burnout rate is getting very great in aged care. I work in hostel and community, and in my sector out of the eight there are at least four who agree that they are burning out or are already burnt out. I see it in the faces of other people, but management do not see it, because they only see what they want to see. It is becoming a big problem. Of these girls that I know, the youngest is 49 and the oldest is 62. So it is not easy.

Ms McKenna—The ageing of our work force is a huge issue for us. There are many people of my age and older. We really are suffering due to the age of the staff. Having an ageing staff brings with it a whole range of other problems, such as long-term illnesses and serious illnesses among your staff. That just compounds the problems that you have.

Senator McLUCAS—You have talked about industry wide benchmarks for minimum staffing levels. I understand the issues of staffing and skills mix and I think you have made that point very strongly. But how do you benchmark that?

Mr Holmes—There needs to be an amount of work done on this issue. In the public hospital system here in New South Wales we have what is called a reasonable workload. We are developing specialist tools to try to measure what is a reasonable workload. The aged care industry is a different circumstance but there needs to be significant work done on establishing the staffing level and skill mix you need to look after the residents to ensure the quality of care. We have seen various models of ratios in other states as well. I am constantly asked by members in the aged care sector: ‘When can we get a reasonable workload and when can we get a ratio of residents to staff so that we can actually have something to measure us against?’

It is an industry that, whilst connected, can be very isolating, particularly for assistants in nursing. They do move around and they often report to the association their surprise at the fluctuating numbers of staff. Some people make judgments that some private-for-profits have different staffing levels to charitable. Others contradict that and say it is the other way around, depending upon their experience. But there does not seem to be a standard across the industry. The legislation itself does not assist very much at all in terms of its requirements for registered nurse oversight of all the facilities where you have high-care residents. As Christina can probably attest, the statistics for the number of high-care residents in our so-called low-care facilities are clearly there, and that number is growing. The fear is that those residents, whilst enjoying ageing-in-place, as it is called, are not enjoying an increasing standard of care that they require as they age and deteriorate.

Senator FORSHAW—I just want to check on your case with the New South Wales Industrial Relations Commission. Your submission came to us back in August last year but, of course, committee hearings had to be rescheduled because of the election. What has happened with that case?

Mr Holmes—The case is still to be determined. We understand that that is close. There is a short hearing next week, which will be about where it will line up with the public hospital rates of pay and negotiations in that area. We hope that we will see an outcome from the full bench very shortly—certainly within the next month.

Senator FORSHAW—I have one last question but I do not want to open up a whole issue that takes too long. We had some evidence from the AMA, the medical profession, which expressed some of their concerns, including the problem that a lesser number of doctors were interested in working in the aged care sector, the problems they claim of levels of remuneration and so on. As members of the Nurses Association are obviously the frontline in providing care and treatment in nursing homes, do you have a comment about what is happening between your members and the medical profession?

Ms McKenna—We have a very good relationship with the doctors in my nursing home but just in the last six months two doctors have told us they are not taking any more patients. We received a letter yesterday from another doctor to say he is closing down his practice as he has been unable to sell it.

The doctors are in a similar situation to us. The GPs who like to come to nursing homes are an ageing group, and they certainly are falling off. In general practices in the area in which I work, there has been an increase in part-time positions and most of those doctors do not want to take on visiting nursing home patients.

Senator FORSHAW—Is that putting greater and greater pressure on the nursing staff?

Ms McKenna—Yes. It is much more difficult to find a doctor to come to look after a resident. I have applied a strategy at the moment to try to admit only patients who have their own doctors who will continue to visit them in the nursing home. It is very difficult to find doctors who are prepared to put in the extra time to come.

Senator FORSHAW—Thank you.

Mrs Heath—Could I put in a comment too. I work after hours, weekends and evenings in a large metropolitan retirement village, and it is very difficult to get doctors after hours. We so often send people to hospital because we just cannot get the medical backup.

CHAIR—We are out of time. I suspect that Mrs Heath and Ms McKenna had presentations for the committee. If you have got something you want to present to the committee, we will attach it to your submission.

Ms McKenna—I did actually make a personal submission as well. So you have actually got one from me.

CHAIR—Thank you very much. Thank you for your contributions today and for your submissions.

Proceedings suspended from 12.21 p.m. to 1.17 p.m.

MOORE, Mr Gary, Director, New South Wales Council of Social Service

PRINCE, Ms Tara, Representative, New South Wales Home and Community Care Issues Forum, New South Wales Council of Social Service

REGAN, Ms Christine, Senior Policy Officer, New South Wales Council of Social Service

FREEBURN, Ms Sheree, Member, New South Wales Aboriginal Community Care Gathering

MA, Mrs Janet, Member, New South Wales Aged Care Alliance

CHAIR—Welcome. Do you have anything further to add?

Mrs Ma—I am also a professional officer of the New South Wales Nurses Association.

CHAIR—The committee prefers evidence to be heard in public but evidence may also be taken in camera if such evidence is considered by you to be of a confidential nature. Witnesses are reminded that the evidence given to the committee is protected by parliamentary privilege and that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee has before it your submissions and I now invite you to make an opening statement to be followed by questions from the committee.

Mr Moore—I am going to make a few opening comments. My colleagues will take some details of questions and other comments. You have two submissions—one each from NCOSS and the New South Wales Aged Care Alliance. In relation to some of the key things that we want to emphasise to you, in terms of work force issues in ageing community care we all know of the shortages that are emerging in aged and community care services and the desperate need—beyond perhaps some of the shorter-term measures that have been taken in recent times by governments at the Commonwealth and state levels—to have a much longer-term approach to work force development dealing with skill shortages and looking at the growth areas within these industries, broadly speaking. There are some particular issues in relation to Indigenous workers and workers from culturally appropriate backgrounds, given the significant number of clients using the aged and community care systems from those population groups. The second area that we want to emphasise is the continuing inappropriate placement of younger people aged under 50 years in residential aged care facilities. In New South Wales our current estimate is that about 450 people are in that situation.

In relation to the Home and Community Care program, there are a number of things that one could say, but there are two main things. Firstly, we believe that we still are meeting only about 50 per cent of the identified need in the community care system through the Home and Community Care program. Certainly the Commonwealth CACP packages are of assistance, but even if you put the two things together demand is still far outstripping supply; and, as we all know, with the ageing population, if we do not do some significant things we will have massive problems down the line. In New South Wales we also have the situation where the major provider in community care, which is the Home Care Service, is struggling to meet increasing demand, and we have instances of unfortunate rationing of services, which seems to be getting worse at this point in time.

Other issues which are of particular concern in this arena are the transport needs of people in residential aged care services. NCOSS recently produced a major report about that, particularly regarding the 30 per cent of people who simply do not have any relatives, family or others who visit them and can offer services. Of course, the community care needs of Aboriginal older people are a significant issue once again, with a lack of services compared with the demand. One of the things we would ask you to note is that once again this year, at least in this state, we do not yet have a signed Commonwealth-state HACC state plan for growth funds. We are now in March in the financial year. The same thing happened last year. It is pretty hard to take, with such a huge demand outstripping supply, that what growth money there is in the system still is not available three-quarters of the way through a financial year.

I will conclude in terms of some things from the Aged Care Alliance submission. There are some issues concerning the Aged Care Standards and Accreditation Agency and concerns in relation to the responses, and timeliness of responses, to the complaints of users. The final thing I want to mention is a positive initiative happening in this state which we think has a lot to offer nationally and certainly in New South Wales if it is expanded. It is called ComPacks and it looks at the health-community care interface where we have community options: employees working as brokers, helping with discharge planning from hospitals in New South Wales. It is quite clear from the evaluation of the trials that the success rate is incredibly high, with good placements and a lowering of the recidivism rate in terms of return to hospital. We think that in that area, with health and community care systems working together, there is something to be said about having a major focus nationally on that sort of initiative.

Senator KNOWLES—Ms Freeburn, I would like to ask you a few questions about Aboriginal care. I come from Western Australia, so, having the whole state of Western Australia as my electorate, I see a few requirements in that area. One issue in particular comes to mind: a great nursing home up in Derby. Their funding was put at risk a number of years ago because they were not seen by the bureaucrats to be ‘fitting inside the dots’, if you want to put it that way. The behaviour of some of the residents was inappropriate to what they would expect in a nursing home; even their attire was unacceptable. They did not like sitting in their rooms; they wanted to sit out on the veranda or they wanted to sit under the tree—all of those sorts of things. I had a bit of a battle many years ago to try to get them to understand that providing proper and appropriate cultural care to those people does not necessarily fit with what we would regularly call an aged care facility. That is a very long preamble, but I am asking whether or not you think that that type of culturally aware care, with latitude for what people really want, is now being provided in New South Wales; and where it is being provided.

Ms Freeburn—You ask where it is being provided. Rose Mumbler, for instance, located at Nowra, is an Aboriginal facility. It is Aboriginal run, and it has been developed by Aboriginal people. The workers are Aboriginal and the residents are Aboriginal. We have another location called Booroongen, but in my view it is not specifically working. We have a 90 per cent non-Aboriginal residential rate there. But, with more time and more funding and resources, I think we could improve on that and have more Aboriginal people there.

One of the issues there is the locations. We have a lot of people out west who want—who need—to go into residential care and just cannot get access to it, because it means leaving their homes, their regions and their families. Aboriginal communities and Aboriginal people do not particularly want residential care anyway, but, when we get to the point where we need it, we would like to be able to have something that is culturally appropriate, that is close by and that has Aboriginal workers providing the care. Unfortunately, that is not around.

Senator FORSHAW—Where is Booroongen?

Ms Freeburn—Booroongen Djugan is located in Kempsey.

Senator FORSHAW—Yes, I have actually been there.

Senator KNOWLES—So are they the only two in New South Wales?

Ms Freeburn—Yes. There is another residential care facility out at Gilgandra, but that has a different type of focus. It is more short term and more of a respite type of thing. The residential care facility at Gilgandra is also funded differently. It is funded for 20 beds, so it does not have to have 20 people in there constantly every day, whereas the other locations do have to be at full capacity every day. The place in Gilgandra certainly works because it is a bit more flexible. There is that bit of time, if you like, where some people can leave and go home for a couple of weeks, and that allows somebody else to come and stay for a couple of weeks. But they are the only Aboriginal-specific residential care facilities available in New South Wales.

Senator KNOWLES—Bearing in mind what you said—that a lot of people do not wish to go into residential facilities—how would you suggest that one could plan for those who do end up having to go into residential care, particularly considering the vast kilometres between places in Australia, and how could one try to second-guess which people are going to have to be put into care?

Ms Freeburn—Quite often the HACC gathering group have this discussion. Our view is that in some areas there is the capacity for an Aboriginal residential building or program to be funded and set up, but in a lot of areas we do not have the Aboriginal population to keep that full. So we think that things like a specific wing or a specific area in local nursing homes or hostels—where five or six specifically Aboriginal beds, depending on the population, could be set aside—would help address some of those issues in our communities. Our people would know that they were going to go into an Aboriginal-designed area that has Aboriginal staff, where the staff are trained up the same as everybody else. It does not actually need to be separate, but it needs to be set up in such a way that, if these people want to be separate and do their own thing, they can do that.

Senator KNOWLES—How imperative is it, in your opinion, to have Aboriginal staff as opposed to trained staff who are culturally aware and sensitive to the requirements of Aboriginal people?

Ms Freeburn—In my opinion it is imperative to have Aboriginal staff. Aboriginal staff actually address a lot more issues than just carrying out their required duties—it entails the emotional care of our elders, which no non-Aboriginal person with any amount of cultural awareness training can address. There are also our historical conversations, if you like—some of our elders with dementia go back to things that have happened in the past. Aboriginal people are much more empathetic, if you like, and we deal with it much better, which is not surprising. There is also the guarantee of no judgments, which is a concern for our elders.

Ms Regan—In my role at ANCOSS, I support the Aboriginal gathering. The Aboriginal gathering developed a policy statement—it was released in 2002 and we are currently updating it now—which says that, for Aboriginal people, Aboriginal workers are absolutely imperative at all levels. It is the shared history as well as the understanding and the nonjudgment. For Aboriginal people those are the major barriers in using non-Aboriginal workers. That has been consistent across the state, hasn't it?

Ms Freeburn—Yes.

Senator KNOWLES—But there are examples, though, that I have experienced where there have been good and empathetic workers and the Aboriginal people have absolutely loved them. What I am posing to you is that it is not just simply that cut and dried if, at the end of the day, it is the difference between having the workers and not having the workers. It is important to have them well trained, empathetic and understanding and for them to build up that rapport with the residents.

Ms Freeburn—While our communities and Aboriginal workers agree with that statement—sure, it is important to have the staff trained in the areas and, if they are non-Aboriginal staff, to train them up as best we can with cultural awareness—at the end of the day, if you go out and ask an old lady, 'Who are you going to be more comfortable with in terms of answering questions or talking?' she is going to tell you, 'An Aboriginal person.' We do have lots of Aboriginal people out there who do not want to use Aboriginal services. We respect that and we work with that as best we can. But there are more people out there who want Aboriginal workers, Aboriginal services and Aboriginal support. Talking about our elders in aged care, I should say that I believe our way of thinking is more around trying to second-guess their emotional levels. If you have somebody with quite severe dementia, they might not tell you that they prefer an Aboriginal worker, but it could create behavioural problems.

Senator KNOWLES—To come back to my original question, which I do not think we got to the bottom of to start with: is there enough latitude being given in the home that you have been talking about to cater for the traditions and behavioural differences of some of the aged, or is the system too rigid to be able to accommodate them?

Ms Freeburn—I personally think that the system is too rigid in its guidelines. While we try to cater to the cultural needs of those in homes, there is a concern for those running the homes that, if funders find out about some of the things we need to do to help our people, they run the risk of being investigated and having their funding questioned.

Senator KNOWLES—That is where I had the barney with the department years and years ago—about the Derby case. They were threatening to defund that facility because they did not fit what is the norm. Eventually they said, 'Oh, well, I suppose that's right. We can't make people do what they are not used to doing'—particularly as they get older and regress to other things that they might have done in the past. That is why I was asking the question—to see whether we are still confronted with that problem or whether we have broken that cycle and accommodated the differences.

Ms Freeburn—I do not think we have broken the cycle. I think we still have that problem. We have quite a few elders who have challenging behaviours due to dementia, and we have nowhere to place them. They cannot go into the existing residential houses, because they have behavioural problems, but there is nowhere else to put them.

Senator KNOWLES—I was thinking more specifically about the Aboriginal-specific one that you referred to.

Ms Freeburn—They cannot go there, because of their behavioural problems. The funding guidelines actually dictate that. It is not the community saying that we cannot deal with it; it is not the community not having enough flexibility to be able to deal with it or at least attempt to deal with it. They are just told that they cannot have somebody. I understand the safety issue and all that. We all look at that. However, if we have somebody who wants to stay in their community but still needs residential care and there is an Aboriginal centre there, we think that we should be able to have the flexibility to at least try. If it does not work, then we will admit it does not work and move on to another way of addressing those issues. But at this stage we do not have the flexibility to be able to do that.

Senator McLUCAS—I want to continue on that theme for a little longer. In Queensland there was a program that the Commonwealth funded—and I am advised that it has recently stopped funding it—where an Indigenous aged care worker was employed by Aged and Community Care Queensland, but with direct funding from the Commonwealth. Did you have a similar operation here that any of you are aware of? That person's job was to work with residential aged care and community care, but mainly to help through the accreditation process. You did not have a similar system here?

Ms Freeburn—No.

Mrs Ma—The work force issue was not covered in the alliance's submission. The alliance put in a submission in August last year, and a few things have happened since then. I wish to have this opportunity to share some thoughts with you. As you are aware, the care needs of our aged care residents have been very complex and are beyond the level of training that an assistant in nursing can deliver.

In New South Wales the key stakeholders include the industry employer association, the nurses association and the TAFE, as well as licensing bodies such as the Nurses and Midwives Board, NMB. In the last two years, we have been working hard to develop a vocational training order for traineeships for enrolled nurses, specifically in aged care. That took us two years to get through. In New South Wales our enrolled nurses in the public sector have trained as enrolled nurses but it is not an appropriate model for aged care. If aged care staff leave the aged care sector to go into the public sector to do enrolled nurse training, we lose one person in three. After a taste of working in the public sector—better money, more resources—they do not return to the aged care sector.

In New South Wales we worked hard for two years to get the vocational training order. That was endorsed in December last year by the New South Wales Department of Education and Training. Unfortunately, until now, March, no aged care sector has been able to set up that traineeship. It is the same training as the public sector enrolled nurse but it is for aged care. The reason is that there are real barriers to accessing Commonwealth funding.

We welcome the minister’s initiatives on a lot of funding issues, as well as increased training in the workplace and upskilling existing staff, but most of our existing aged care workers have a certificate III or above. With that, they are not allowed to access Commonwealth funding. No aged care sector can apply to have a trainee for 12 months full time and send them off to TAFE to do their enrolled nurse training. A lot of our existing aged care workers want to go on to further training to enable them to deliver the care the resident needs, but there is a real dilemma with the barriers to accessing Commonwealth funding.

Another issue is that the enrolled nurse in aged care is not listed in the rural and regional skills shortages list. That is another barrier in rural and regional areas. Even with shortages of staff, they are not able to take up this new initiative or traineeship. I am not sure whether the minister is aware of that. We have written to the minister and we are hoping to get some result. We are trying to get both the state government and the Commonwealth government to work together, because for traineeships the funding comes from both, but existing aged care workers are not entitled to funding from either one of them.

Senator LEES—Would we be able to have some copies of what you have said?

Mrs Ma—I have some notes here that I am able to share with you. It is very new, like I said. That is why it was not in the Aged Care Alliance submission. It was only endorsed in December, but it is March now. No aged care sector is able to overcome all those barriers.

Senator McLUCAS—Essentially, the barrier is the fact that the person who may want to access that training already has a certificate III and therefore is trained enough already, according to the guidelines?

Mrs Ma—To access the funding initiative from the state government they have to be new employees, new entrant trainees. But we have an aged care work force. The government want them to be upskilled. Most of them have a certificate III or above, and they want to move on and do more. But there is no career pathway for them.

Senator McLUCAS—What qualification do you get if you complete one of these traineeships?

Mrs Ma—The traineeship is the same as for the public sector enrolled nurses. It will be regulated by the NMB, the Nurses and Midwives Board. They will be licensed. They will be able to administer medication. That is a golden opportunity to free up the registered nurses to be clinical leaders and to develop therapeutic relationships with the residents. But unfortunately we are at a real crossroad now where we are not able to overcome those barriers.

Senator McLUCAS—That leads me to the other issue I wanted to talk about, which is medication management. What is the situation in New South Wales for medication management and what should happen?

Mrs Ma—In New South Wales endorsed enrolled nurses are able to administer medications under the supervision of registered nurses. I am aware that in a lot of aged care facilities they do use unregulated, untrained people to administer medication. If the resident is capable of managing their own medication regime, that might be fine. As a nurse, from a nursing perspective, I can say that giving out medication is not as simple as just pressing the Webster pack and shoving it at someone. It is not as simple as that. You need to be aware of the entire anatomy and physiology and what the person's complexity is. You need to know about the side effects of the drug, the efficacy of it—whether it is working—and when not to give that medication. It is not as simple as just giving it out. As you are aware, a lot of our aged cared residents are not cognitively able to direct someone to do that. If you give the medication to that person, they just take it. There is no legal requirement to stop a facility from employing an untrained person to do that, particularly in a hostel situation. I think that is pretty alarming for registered nurses. They find it really stressful to see these sorts of things happen, particularly in a hostel situation where they have high-care residents who are managed by unregulated workers who do not have the knowledge and the skills to do the job.

Senator LEES—I have been looking at your submission, particularly the section enclosed on young people in nursing homes. You have listed a number of examples of cases where people are inappropriately placed. I think the number you have is about 1,300 young people in nursing homes in New South Wales—with, I suspect, that number again in the community, where pressures are building for alternative care. In Western Australia we saw a model of care that was Huntington's specific, MS specific and brain injury specific. Basically, in most cases you would not know they were not just ordinary housing. They catered for between four and about 25 people; I think the Huntington's specific facility had about 20 residents. Is that the model of care you would like to see in New South Wales?

Ms Regan—Basically we would stay with the current disability policy at the moment, which is for small groups. NCOSS would support smaller groups of people being supported and integrated as much as possible in the community. The difficulty in actually developing larger groups of 20 or 25—

Senator LEES—They were in separate houses, but the houses were linked by walkways. I do not think we actually saw more than two or three people in any of the houses, but they were integrated.

Ms Regan—As you will see in our submission, one of the difficulties is we think we have developed a proposal to put to both the Commonwealth and the state on how to relocate the people who are receiving Commonwealth subsidies who are already in nursing homes, but we suspect that twice or three times that many people are actually living in nursing homes for all manner of reasons—some historical, some family et cetera. We would be wary of developing one proposal or one model that meets those needs because of the obscure nature and the range of disabilities. I am sure you have heard this before, but some people are so desperate, especially ageing carers, to ensure that their younger person with disabilities is cared for that they will do deals with service providers who, while they might be hesitant or resistant in the face of alternatives, might then provide inappropriate or appropriate service provision. The difficulty there is that that is probably a happy relationship, that the service provider does their utmost and that the family is cool. What we are mostly concerned about though is that the opportunities for that younger person, who is likely to reside within that facility for many years, are hugely reduced; their involvement with the community is restricted.

Senator LEES—Why would that be? I am thinking about what we saw in Perth: they were out virtually every day.

Ms Regan—We do not see that model in New South Wales. If we were to have models like that they certainly would be under consideration. The other issue is that New South Wales is currently looking at its models of supported accommodation. There is a discussion paper by the state government that is out at the moment and it is looking at all manner of proposals. Certainly the disability sector in New South Wales will be pushing very much for as small as possible and as integrated as possible, so if those models in Western Australia were meeting those goals then they would probably be acceptable in New South Wales. However, we are a little concerned. There are some dangers in clustering. There are some dangers in creating congregate care that restricts opportunity and restricts involvement. It can also restrict involvement of the family, and we would need that to be monitored. In New South Wales there has been a problem with disability services in that they have not received any deliberate or structural monitoring for over four years. We are very concerned that should processes be set up without that monitoring and quality at the front end services would again be relaxed and we would get into institutionalisation.

Senator LEES—You mentioned the discussion paper by the state government. Do you have a copy of that with you?

Ms Regan—I do not have it with me, but I can get it to you immediately.

Senator LEES—If you could pass that to the committee, it would be good. I know there are other members of committee with questions, so I will finish with a summary. You are saying that you would not support a cluster model such as we saw in Western Australia, where the entire courtyard of houses, where you drive in, are all catering for people with MS who are either living with their family or, in some cases, sharing the house with someone else with MS. The entire section was able to take about 10 to 12 people.

Ms Regan—There are economies of scale and we would be interested in looking at the most cost-effective way of providing services. However, the disability sector in New South Wales is clearly saying, ‘Very much smaller, and beware of clustering because there have not been good experiences in New South Wales in providing clustered services.’ They are very concerned about inappropriate proportions of people with disabilities in the general population and then having those facilities labelled.

Senator LEES—By talking about the disabilities sector, you are not talking about parents of people who have a disability? Who in New South Wales is saying that this is not an option? Unfortunately I am not able to stay as I have another commitment, but later we have a number of parents coming, all of whom have presented to us basically what are clustering models.

Obviously the parents are pushing for a different model from the one of the disability sector. Who are you referring to?

Ms Regan—We have done quite a lot of work on this in the past. The disability sector that I am talking about is the peak organisations who can represent some parts of the industry—certainly disability organisations such as the Council for Intellectual Disability, Family Advocacy, the Multicultural Disability Advocacy Association and the Physical Disability Council, for example. There is a conflict, and I absolutely, openly acknowledge that. Where parents and families—and clearly people with disabilities—have so few options, they will go to options that may not be in their best interests. In the disability sector in New South Wales, in the absence of any really supportive processes, we would be looking at getting it right from the outset rather than going to the next least problematic solution. If we were to see some more creative models and have a look at how that was, I would be worried about absolutely desperate families seeing a solution.

Senator LEES—You are worried that they are going to be pushed into these cluster models when they really do not want them—they do want their young person in a flat on their own in the community.

Ms Regan—To have opportunities. I cannot speak for them and I do not want to cut off their opportunities.

Senator LEES—Perhaps someone else will ask the questions later on.

Senator McLUCAS—I am trying to get an understanding of what you mean by the word ‘clustering’. I think words are used differently in different areas. What is a cluster?

Ms Regan—A cluster might be where people with disabilities do not live in the same room or the same building but where there might be buildings that are either in very close proximity or on the same property. That creates a small identified facility. In New South Wales we have not had good experience with disability institutions so there is a lot of hesitancy or resistance to anything that dresses up what could be institutional care. That is not suggesting that that is.

I do know that in New South Wales there are people who are considering how that might work, but the models have not yet been put forward. The document of the Department of Ageing, Disability and Home Care is simply posing 10 different models and asking the sector—or anyone who receives the paper—to provide feedback on whether that model might be appropriate for people with disabilities and what kind of people with disabilities might receive benefits from it. They are even posing a question about medium- to high-density living. They really are putting out exactly how people would like to go.

Until now, the position has been that we would look at a range of options rather than one particular option. Even from our discussion this morning with the minister, we can say that, while group homes have been the way to go in New South Wales, it is now recognised that that seems to be the only way, and that does not meet everybody’s needs. We do need flexible, innovative service responses.

At the high end of need that we are talking about with younger people in nursing homes, clearly we need high-level medical intervention and possibly very intensive supports that at the moment in New South Wales are not available in many other ways. That is why, in the NCOSS response, we went to some length in trying to describe what the problem is. There has been a working party in New South Wales called Younger People with Disability out of Nursing Homes who have been actively advocating on this issue for some years. At times we have had good involvement with the state department, at others lesser involvement. We are still working on that.

Senator McLUCAS—It seems to me that it is not necessarily the architecture of a place but the culture of care, if I can call it that, that is more relevant. Would you agree with that?

Ms Regan—I would say that, but there are some forms of architecture that lend to protective behaviours. We would say that, where fewer people are involved with people with disabilities, the risk is higher because the standards can be relaxed. Where people with disabilities themselves may not be in a position to advocate or complain, the risks escalate. That is the danger. That is not to say that always happens, but trying to maintain an open and accountable culture of care within a closed community is incredibly difficult, if not impossible.

Senator FORSHAW—I must thank you for the very detailed submission; there is a lot of good stuff in there. I am particularly pleased that you have picked up on some issues that probably have not been addressed as much as some of the main ones, particularly the discussion about transport needs. That is very useful. There is a comment on page 17 that the New South Wales Audit Office has been reviewing the Home Care Service and is due to report shortly. I appreciate that your submission was back in August. Can you give us an update on what has happened there?

Mr Moore—The Audit Office did report recently. It was actually quite revealing about Home Care—and I alluded in my opening comments to the rationing process that is going on in the Home Care Service of New South Wales delivered services. The Audit Office found that it is simply about the mismatch of demand and supply. But, once again, it also raises issues—as, I think, Janet and others have raised—about the appropriateness of skills of staff and the locations across New South Wales. It is quite a detailed report.

Senator FORSHAW—The committee could probably obtain a copy, but if you could send us one that would be good. I seem to recall that there have been issues in the past—and I am not sure whether they have been finalised—regarding wage levels and the impact of awards and rates and how those issues were going to be addressed in terms of funding. Has that all been resolved now?

Mr Moore—It has not been resolved terribly satisfactorily, because, within the HACC program, as you would be aware, more broadly speaking, both the social and community services award and the public sector award operate in terms of Home Care and the sector as a whole. There have been some significant issues because, unfortunately, the Commonwealth decided not to raise additional funds for its share of the funding of the HACC program in general. New South Wales has had to meet those costs—and has decided to meet those costs. There is an argument that therefore goes that, because New South Wales have had to do that, they have had to withdraw money from their own statutory service—the Home Care Service. Christine might want to add to the detail.

Ms Regan—Home Care have their own award.

Senator FORSHAW—They have been around for some time. That goes back to the days when it was known as the Home Help Service.

Ms Regan—It grew from a volunteer service. I would like to pass to Tara in a moment to explain some of the problems that we face with Home Care, which the audit report revealed. A couple of the big problems were the receipt and treatment of complaints. They found that, while the complaints themselves were being treated in an acceptable manner, there was no way to assess and collate the complaints so that there could be systemic change within the organisation. That was something that was recommended in a previous performance audit in 1996. the other big issue was about waiting lists, because of the demand. Home Care has changed the way they do their intake. Large parts of Home Care, mostly metropolitan, have what they call an intake and referral service, which is a call centre. Much of the report dealt with the problems in trying to access the call centre, particularly from a consumer viewpoint. Tara can probably give us some more information on that.

Senator FORSHAW—If we get a copy of the report we can look at it, but if you wish to comment you may.

Ms Prince—The major issue is that Home Care, through Sydney metro, do not keep a waiting list, so it depends on when you ring whether you get service. Also, the impact of having no waiting list is that there are obviously extreme difficulties accessing support, particularly for people leaving hospitals. The social worker would refer a person to Home Care and, because there is no service available at that point, people go home. They do not have anybody to advocate for them later on, they do not get to wait—it is just a matter of whether they ring again at the right time as to whether they will get service. There is also another problem with the RAC in that it is a metro service. Where Home Care cannot meet the support of the person, they do not have any networks with any of the local areas, so they get referred to Carelink, which is an information service. So there is no ensuring continuity that that person will end up getting support. Often that support is somebody needing a shower a few times a week, and they are going home without it. That is having huge impacts.

Senator FORSHAW—I have one other question for Ms Freeburn. You mentioned the nursing home aged care facility just outside Kempsey. I recall visiting that—if it is the same one—some years ago. Is Booroongen the name of the facility?

Ms Freeburn—Yes.

Senator FORSHAW—Is it just a nursing home, or does it have some other hostel type accommodation?

Ms Freeburn—Booroongen Djugan has different levels of accommodation. There is nursing home level, where people can live singly, and hostel level, where people can share.

Senator FORSHAW—It is the same place; I recall it. I am interested in the comment you made, because I am pretty familiar with the Kempsey region. As you said, the facility has about 90 per cent non-Aboriginal residents. Can you explain a bit more what the problem is? As I understand it, it was established primarily for Indigenous Australians. It is also open to Aboriginal people from anywhere, is it?

Ms Freeburn—Yes.

Senator FORSHAW—You have a large Aboriginal population in that region and there are a range of other services, such as the medical service and the rehab centres. What is the problem?

Ms Freeburn—I think the biggest problem there is the fact that Aboriginal people do not want to go into nursing homes. Hostel accommodation is a different situation, but it is also about the short term. When Aboriginal people get to an age and feel that they are close to the end of their life they want to return home. They want to be at home with their families to die. I think the biggest problem with Booroongen is the fact that there are no facilities for families. If the facilities allowed for families, particularly for our elders to even have their grandchildren visit and stay overnight, that would make a difference. It would offer something different.

Senator FORSHAW—But it is not being utilised by the local Indigenous population of the mid-North Coast?

Ms Freeburn—There are Aboriginal residents from that area in that facility, but quite often they want to go home. They want to go home and be with their families.

Senator FORSHAW—It is a pretty modern facility, isn’t it?

Ms Freeburn—It is a very modern facility.

Senator FORSHAW—And it is fairly large?

Ms Freeburn—From my understanding the newer facility, which is a two-bedroom unit near the roadway, is a bit more successful than the other parts. You can actually have two Aboriginal people in there. The idea was that, if there is one elderly person in there, they could also have family stay with them and still have the privacy of separate bedrooms. I think the biggest problem with the facilities is the fact that there is no allowance for families.

Ms Regan—I would add that the Productivity Commission report on government services shows that New South Wales has a much higher proportion of uptake of packaged care—that is, CACPs and EACHs—amongst Aboriginal people. That indicates to the gathering that people are much more comfortable in receiving the care they need but in the place they need it and by people with whom they are familiar, and we would support the ongoing acceleration of packages into the Aboriginal community.

Senator McLUCAS—The NCOSS submission talks about your concerns about the complaints mechanisms. You were talking about the relationship between the agency and the complaints mechanism. What is the problem there? Do you want to elaborate on that issue?

Mrs Ma—I might take this opportunity to share with you my personal experience. The complaint resolution scheme definitely is not working. I will give you a good example, a real one. I live on a battleaxe block. My driveway is about 300 metres from the front door and is at the back of everybody, so normally I do not see what happens in the driveway. A couple of years ago on a really freezing cold winter night, when we were going out we saw an elderly man lying on our driveway in his pyjama shorts. I got out of the car and had a look. Luckily, he had an armband and told me he was from a nursing home two blocks from where I live. Without even having to ring them I helped the old man to get up and put him in our car. I drove him back to the nursing home and he thanked me. He thought I was a taxi driver. I did not take much notice of that, but I did think that if we had not been going out that night that man would definitely have died from hypothermia, because it was a freezing cold night and he only had on pyjama shorts. I did not take any notice and did not write down his name or anything.

Then, a few months later, in summertime, I went for my evening walk with my husband. I saw another old man—with his pyjama shorts on and a urinary bag tacked to the upper part of his leg, which was most undignified—running down the street, and behind him there was a nurse chasing him. The faster she ran; the faster he ran. He was running towards the main street, Croydon Road, near Hurstville, where there is a lot of traffic. I immediately took charge and, being a registered nurse, said, ‘You go back to the home to get more help and I and my husband will follow this man and calm him down.’ So we followed him, and the nurse went, then came back to the street with three other nurses in a car and tried to force the man into the car. Luckily, the poor old man thought my husband was a taxi driver and said: ‘These women want to kidnap me. Help me.’ My husband then managed to convince him to get in the car and took him back to the nursing home. My concern is that the nursing home is only two blocks from where I live and the nurses there are telling me the facility is not up to scratch. You walk in and smell urine. The residents are in and out, they have dementia patients—and yet there are no security measures. Yet they achieved a three-year accreditation. I went in there many times. Nobody asked me any questions.

So I decided to write a letter. This time I got the armband details and wrote to the Department of Health and Ageing. I got a standard reply, saying, ‘Please go to the Aged Care Complaint Resolutions Scheme.’ The standard letter—everything was standard. I rang the number. It was one of those ‘you want this, buzz number 1 or 2,’ and I thought, ‘If I were an NESB person I would probably not have a clue how to do that.’ I finally got onto that, and again they were saying, ‘You have to get onto the mediation action.’ I said: ‘No, I am not a relative of the nursing home resident or anything. I am just a concerned member of the public, because I have seen so many incidents and the nurses there are telling me that the proprietors are not doing anything and the agency has accredited them for three years. How on earth can a facility have three years accreditation when there is no security to safeguard those residents?’ I just looked at the facility and thought that if my father were in there I would think he was safe and warm there. So I took the trouble to write to the Department of Health in New South Wales. Two years ago we still had the Nursing Home Act and the state government still regulated the nursing homes in New South Wales, but not now. I think that act has been repealed. So then they took action and they did find all those issues I raised. Even the local police station was well aware: if the nurses ring them they look out for where the residents are. The nurses have to go with their own cars to find the residents. That tells me the complaints resolution scheme is definitely not working, and I cannot explain why this place gets three years accreditation. I really cannot. This is my personal experience.

Ms Regan—From the Aged Care Alliance viewpoint, I would like to add that we have bimonthly meetings—six a year—every year. We talk about the complaints mechanism for residential aged care at at least every second meeting, with stories. At the table for the Aged Care Alliance, we have industry people—vigorous industry people who support and promote their industry—tertiary education people and a lot of consumers and consumer organisation representatives. The very strong message that NCOSS gets from the Aged Care Alliance consumer groups is that the complaints mechanism is not accessible to people and not responsive. There are some disjoints between making a complaint, how that goes through the scheme, whether or not it gets to the agency—as Janet has described—and then how that is enacted. That is very consistent.

Senator McLUCAS—Another issue that has been raised with us is the fear of the families of people who are in residential care that, if they do pursue a complaint with the complaints resolution organisation, there may be retribution. Is that a position that NCOSS has a view on?

Ms Regan—We probably do not have a view on it, but certainly we receive fairly consistent reports of that through stories at the Aged Care Alliance meetings. I might say, though, as well, that I undertook the transport project that was attached to the submissions, and in the course of doing the transport project I found some excellent examples of resident committees where the residents were actively encouraged in a fairly independent way to have their own say and have their decision making. They were the residents who responded to the transport surveys that I sent out over and above the providers as well. The criticism of poor operators—we are only talking about poor operators really; we are not talking about good operators or exemplary operators—was that it was a ‘tick the box’ thing; that they get a committee together, that it is the cronies, whoever they might be, and that that is a closed committee to most of the population of the facility. That also was fairly consistent feedback that NCOSS receive. We then do our best to feed it through whatever channels we can. NCOSS do not receive specific complaints. We receive sector complaints and stories, and we pass on sector trends, if you like.

Senator McLUCAS—Mrs Ma, the point you made that the complaints process should be available to more than families or residents themselves is a good one.

Mrs Ma—I spoke about the mediation process. I am just raising a concern and drawing to their attention the issues here. I work full time and yet in such a short time I came across two incidents that I am very concerned about. I believe that if the care is not good enough for my father or mother it is not good enough for anyone. That is how I see it.

CHAIR—Thank you for your submissions and your contribution to the committee today.

[2.14 p.m.]

MacLOCHLAINN, Ms Ann, Policy Officer, Mental Health Coordinating Council

McKAY, Dr Roderick George, Private capacity

VAUGHAN, Ms Vanessa, Manager, Sydney Support Services, New Horizons Enterprises Ltd

CHAIR—Welcome. Do you have any comments to make on the capacity in which you appear?

Dr McKay—I am here with the consent of my organisation, Hope Healthcare, but I am not actually representing them.

CHAIR—The committee prefers evidence to be heard in public, but evidence may also be taken in camera if such evidence is considered by you to be of a confidential nature. Witnesses are reminded that the evidence given to the committee is protected by parliamentary privilege and that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee has before it your submissions. I invite you to make an opening statement, to be followed by questions from the committee.

Ms MacLochlainn—MHCC is the state peak body for non-government organisations working for mental health throughout New South Wales. We represent the views and interests of over 140 NGOs in the formation of policy and act as a liaison between the government and non-government sector. Our member organisations specialise in the provision of services and support for people with a disability due to mental illness. We are very concerned about the needs of older people with mental illness. This group can be broken up into two broad categories—firstly, older people with late-onset mental illness such as dementia and late-onset depression; and, secondly, older people with longstanding mental illness. This refers to people who have a history of ongoing mental illness and who are now in the age group 55 years and above.

The group of older people with late-onset mental illness have traditionally received more focus than people with longstanding mental illness. However, even for that group who have received more focus there are still major concerns related to service provision. The report of the Legislative Council inquiry into mental health services, which you are probably familiar with, identified three main concerns relating to people with late-onset mental illness. This was based on evidence presented to the inquiry. The three main concerns were the effectiveness of general practitioners in detecting and treating dementia and depression in older people; the access of older people with mental illness to Commonwealth and state funded services; and the inadequacy of accommodation and support options for elderly people with confusion and other mental disturbance.

In 1999, we at MHCC conducted some preliminary research into older people with longstanding mental illness. We identified that the following improvements were needed: increased training for staff in both mental health and aged care sectors in relation to the combined effects of mental illness and ageing; improved case management of clients; the use of a more comprehensive assessment tool that includes mental health and substance abuse issues as part of the assessment process; increased independent living skills training; and increased community resources. Even though that was done in 1999, unfortunately those improvements are really still needed.

There is an urgent need for increased training for staff of residential aged care facilities in the care of both people with mental illness and those with dementia. The needs of these residents are not currently being met to an adequate degree. This can cause deterioration in mental state and cognitive functioning, with a consequent decline in safety and quality of life. Additionally, when residents with these conditions are not cared for in an optimum manner, the resulting disturbances impact negatively on staff and other residents. This increases the distress for residents and staff and contributes to the ongoing staff shortage.

We note that some young people with disabilities, including disability from a mental illness, are being accommodated in residential aged care facilities. We view this as highly inappropriate for both the young person and the aged care residents, as both groups need care that is specific to their different needs. It is preferable for both groups to be in the community in an environment that encourages as much independence as possible and which prevents further institutionalisation.

We contend that many aged care residents could continue to live in the community for much longer periods if adequate supports were available. These supports need to be flexible enough to respond to the different needs and circumstances of individual people. People with a mental illness of course need different assistance to people with other disabilities. We also feel that, if it becomes necessary for an elderly person to enter aged care, every attempt should be made to facilitate that person in obtaining as much independence and individuality as possible.

We would also like to draw attention to the urgent needs of residents of boarding houses. Many of those are elderly and have mental health problems. The report of the New South Wales Legislative Council inquiry into mental health services that I referred to before found that boarding house residents had major unmet needs for health care and mental health care and also highlighted the unsatisfactory living conditions of most boarding house residents, including lack of privacy, lack of protection afforded by the lease agreements, lack of security of tenure and consequent frequent abrupt moves. This is very distressing for anyone but, for someone with a mental illness, it makes it very difficult for those residents to form the stable treatment and support networks which are essential for recovery from mental illness and maintenance of mental health.

The New South Wales department of health provides clinical services for people with a mental illness. Our understanding is that DADHC provides services for people with a disability due to mental illness. However, there is sometimes a bit of difficulty in where the division is between someone who has got a mental illness and needs the clinical service and someone who needs services for a disability from a mental illness. We are concerned that DADHC does not appear to fully accept its responsibilities for this particular group of disabled people. The result is that many people with a disability due to mental illness fall through the gap and are not provided with the services that they need. Additionally, the current home and community care programs are inadequate in meeting the needs of elderly people with a mental illness. There is a need for continuity of carers and continuity in the routine, and the carers need extra training in meeting the needs of an elderly person with a mental illness. Also, as many of these people are also socially isolated, social activities need to be included as part of their program.

We have had some discussions with the Centre for Mental Health and the New South Wales department of health. They are engaged in a number of initiatives to improve service delivery in the area of aged care mental health. We support those initiatives. I am happy to discuss those initiatives further if you want me to later on. Our main concern would be for adequate resources and funding to be provided to make sure that these initiatives actually translate into really good services on the ground.

Dr McKay—First of all, I appreciate the opportunity to appear before the committee. The submission from myself and Regina McDonald was driven by the fact that we are living each working day with the impact of these issues not just on the people with the illness themselves but on the families, extending right out through the community, really, as well as the professionals that are trying to impact on it. I would like to correct a couple of typographical errors in the submission: with regard to psychogeriatric patients, ‘quite elderly’ has somehow become ‘quiet elderly’ ; and also ‘facilities’ has become ‘faquities’—I am not sure what that means.

The thrust of our submission is that there are very high rates of dementia and mental illness within residential aged care facilities. The figures being talked about have anything from 25 to 75 per cent of residents with significant depression. In terms of dementia, a relatively recent study found that over 90 per cent of residents in nursing homes have at least some behavioural disturbances—a ubiquitous problem. There are very significant deficits in the services available for these people.

Within these groups, there are some populations particularly disadvantaged—and I have outlined those in my submission. These deficits really do extend from residential aged care into the community and transitional care and have the potential to be exacerbated by an increasing focus, which is appropriate, on occupational health and safety in that it appears to discourage services from providing care to this very disadvantaged group.

Although some of the deficits in care can only be solved by providing more resources, we believe there are also systems and planning issues that could be looked at to improve care to this population. These issues include things like the design of residential facilities—questioning why we are still building facilities that are not designed specifically with dementia in mind. Also, there should be systems to ensure that, when facilities or resources are put in place for these people, they do serve those who they can serve best and do not serve only those who it is easiest for the services to serve. There is also a need for improved training of staff and clinical professionals, improved recognition of the non-physical care needs of this population in all settings—residential and in the community; and it probably becomes most pronounced in the community—and a re-evaluation of how the often complex primary health care needs of this population would be better fulfilled. Lots of assumptions are being made about what general practitioners can do, but, on the ground, they do not seem to be possible. This is particularly relevant given the significant work force challenges that all aspects of health related services face at present, which are going to exacerbate problems into the future.

Senator KNOWLES—Dr McKay, could you expand a little on where you think the dementia-specific units are falling down and what you really think is the level of unmet need here in New South Wales.

Dr McKay—I think the level of unmet need is extremely large. My knowledge, which is indirect in many ways, is that most people who need to go into a dementia hostel from a hospital cannot have that happen—they will go into a nursing home instead because they cannot find a dementia place. I believe that a very high proportion of people probably go into high-level care instead of a dementia hostel due to a lack of availability. I cannot give figures for that.

There are a number of challenges in terms of dementia units. The first is that there is no definition around what a dementia unit is, either at high- or low-level care. This in itself creates significant problems. If there is no definition then there are no planning guidelines around that, so you see some excellent examples and some examples where there is a name put to the unit that it is dementia specific but it does not seem to meet those expectations on the ground. That makes it extremely difficult for families to be able to access appropriate care, even if it is available.

There is also a problem in that, when you have good examples of dementia care, part of why they run well is that there is a temptation to use those facilities for a population who can keep those facilities running well. That means they exclude people who will be more difficult. That often means excluding people with mental illness, and our perception is that mental illness often equals exclusion from dementia-specific facilities, especially with low-level residential care. There is no incentive to manage the more difficult people. This is also the case in the community, where funds have been put into the concept of respite care in the community for people with dementia and challenging behaviours, but we have seen that ‘challenging behaviours’ has been defined as anything that is challenging to the carer, and people with dementia do have a wide range of challenging behaviours. Unfortunately, that seems to mean that those with the more challenging behaviours cannot access that care at all, so it is not targeting the group that may potentially benefit most from it.

I think part of that is driven by occupational health and safety concerns. It is something which is coming more and more to the forefront and is pushing people into less and less appropriate care, because the most appropriate care is at home. If providers feel that for OH&S reasons they have to select the people they care for more carefully, that often means that people with dementia, a moderate degree of behavioural disturbance or a mental illness have services withdrawn. So those who need more help are getting less help and therefore they end up in residential care. In a similar way, people in residential care risk ending up inappropriately in acute hospitals due to the same sorts of concerns.

Senator KNOWLES—Ms MacLochlainn, can you expand a little bit on what you have done in your ongoing dealings with the state government about trying to get more funds for people with disabilities?

Ms MacLochlainn—We have been raising the issue whenever we can, in our various submissions and at various forums. Vanessa might like to speak to you about her pilot.

Ms Vaughan—New Horizons Enterprises is the lead partner in a consortium doing a pilot that is funded by the Commonwealth and DADHC. That pilot involves a nominated number of people—I think it was 45—and has been over a three-year period. Its aim was to assist 24-hour residential facilities to continue to provide a service to clients who were ageing and becoming demented. To date the pilot has been going for a year and a half. It took about six months to start the entire process. They have 45 clients on the books and only two of those people have needed to go to an aged care facility at this stage. They broker some services and they are able to broker other agency people to go in. They have increased people's weight by attending to feeding times. They carry out physiotherapy and they also have a gym for people to go to for exercise. They have had a very good outcome from that pilot. That was a DADHC initiative.

The other DADHC initiative that New Horizons is involved in maintains people with a disability who have ageing carers, or ageing issues of their own, in their own homes. We broker other services to go in and provide care and we provide the case management. We also have a group home network in three regions, but I will just talk about Sydney for today. That group home is funded by Health—none of it is out of hours; it is primarily business hours—and we do living skills training there for people with mental health issues. We find that we are unable to provide a service for them if they start to show signs of dementia or any ageing issues. Part of what we are looking at is how we can address those issues, because I have to find aged care facilities to take those people, especially if they have dementia.

Senator MOORE—You said that in the first year and a half of the pilot only two people had to go from the previous place into an aged care facility. Without your services, how many do you think would have had to be relocated into some form of accommodation?

Ms Vaughan—I would not like to speak for the person who is managing that program but it was recognised that there would have been many more—

Senator MOORE—The expectation is that there would have been a lot more.

Ms Vaughan—due to the dementia and incontinence issues, and the lack of adequate eating.

Senator McLUCAS—You talked about transitional care. How does that work here in New South Wales?

Dr McKay—Transitional care is, first of all, still in its infancy in New South Wales.

Senator McLUCAS—I think it is everywhere.

Dr McKay—There are some peculiarities around the way some services are organised that exclude people with mental illness. Some facilities, because they are aged care funded, are officially subacute facilities and therefore they are excluded from providing transitional care—even though the people within them may be very similar to people who, in a different area, would be classified as acute. So there are definitional issues that create blocks.

How transitional care can best serve people with either mental illness or dementia has not been well thought out. It is quite common for someone with dementia, if they end up in hospital, to have a significant increase in their cognitive impairment, which, if there were adequate transitional care arrangements targeting that problem, may well resolve well enough for them to either go home instead of into residential care or go into hostel or low-level care instead of into high-level care. At present, most of those people end up in high-level care, with severe consequences for both them and their carers.

Senator McLUCAS—There is a structural problem but is there also an issue—and this probably goes across all groups—of training of care staff in both long-term and late onset mental illness issues, or dementia?

Dr McKay—Training is very definitely an issue. You see some facilities where it is done very well and others where it is not. In the community in general the level of training seems to be declining, not improving. In general, 10 years ago we were talking to clinicians who were more actively involved at that stage than I. Whereas 10 years ago you could access people in the community with training, now it is extremely hard. That exacerbates the problem. You actually can have people going in to provide respite who actually may make the situation worse rather than better. This is not across the board. I have to emphasise that there are still some very good community services as well. But the training makes a huge difference.

In residential care, though, it really is the training and the facilities. I do not think I can overstate the need to have properly designed facilities for people who have mental illness or cognitive impairment. The design can really reduce or increase the demands on staff. That does not just impact—

Senator McLUCAS—Can you give us an example of that? What sort of thing—

Dr McKay—Sure. The sorts of things are that some facilities which have been purpose designed are designed so that the environment itself orientates a person—it is much more homelike. The person can bring in things of their own. That actually reduces their level of agitation. It probably has an impact on reducing their levels of depression. That actually then reduces the care burden on staff. It also increases the safety for staff, for that resident and all the other residents. Because, in general, facilities have mixed people with all conditions it really does impact on every resident in every facility. There are other facilities which really are still designed with a corridor, which have no orientation and no ability for a person to bring in their own belongings to help make it more homelike.

With the concept of a nursing home, it is probably very good that the name has gone out of fashion because it is not a home, other than in the exceptional facilities. The exceptional facilities are homes. The difference that makes is tremendous. I question why we are still allowing facilities to be built that are not based around these needs. There are New South Wales guidelines for acute hospital facilities. These are not mandated but at least people are starting to look at the needs of people with dementia. I think we need similar guidelines for our residential care facilities across the country so that we are building quality facilities.

Senator McLUCAS—I suppose there is an internal conflict there because I am sure there would be nursing home managers or residential aged care managers who do not want someone’s personal effects because of the issues of cleanliness or something falling and breaking. We want it nice and clean like a hospital.

Dr McKay—There is definitely a balance. At the moment, if a facility finds people with dementia too challenging they can open the door. And that is what they do. If they have a gate, they take it down. It solves their problem; it does not solve the problem for the community. I would love to see a dementia nursing homes or dementia hostels recognised as specialist facilities, whatever that may mean in terms of the funding and the guidelines around what they can and cannot do. But they should also be expected to fulfil that function if that occurs.

Senator McLUCAS—Earlier you talked about training. What are the elements of good training for mental illnesses and dementia? I do not want you to recommend a particular provider! Are there things that will lead towards a good outcome in training?

Dr McKay—The Challenge Depression Project, which was federally funded, has some very good guidelines about things, so it is a document that is well worth referring to. Similarly, there is an article which refers to preventing depression in residential care. It is in *International Psychogeriatrics*, which is Australian based. If you are interested, it is well worth reading. A lot of the elements of training are very basic. It is about knowing how to approach people and how not to make things worse—how to treat them as a human being. It is extremely difficult when we have a work force who are often not from an English-speaking background and a lot of the basics of communication go wrong. There is definitely a need to increase from that in terms of knowing some of the basic impacts on people of cognitive and sensory impairment and ageing. I think that is almost more important than the specific training around mental illness. If those basics were done properly, I think the support services from health could deal much better with mental illness issues. I think depression would be the biggest factor, and psychosis is very important for those people who are going into care more often than they should be. If people had the basics of communication and approach, that would in many ways transfer across to their dealings with everyone.

Ms MacLochlainn—I agree with a lot of what Dr McKay has said. I also think delirium is a very neglected area. It is very misunderstood and very poorly recognised. A lot of aged people are very prone to develop delirium. They do not even have to have a mental illness—although if they have a mental illness or dementia they are more prone to developing it. Any of us could develop delirium if we had pneumonia or something like that—and that is much more the case for an elderly person. I have found that delirium is very poorly recognised. People with delirium are at great risk of falling. They become very confused and frightened. They get mixed up and are not sure what is happening. They become very agitated and it is a very scary thing for them. I find that the staff do not really recognise and understand what is happening. They sometimes think the person is being difficult, going crazy or something like that, whereas delirium is a transient condition and gets worse at certain times of the day and under certain conditions. It is really important that the staff have very good and thorough training in recognising that.

As I said, I agree with everything Dr McKay has said, but in addition we have to acknowledge that there is tremendous turnover of staff and therefore training needs to be ongoing—it needs to be repeated. Whenever a particular resident has some kind of health need, mental health problem, dementia or delirium and a consultation is done by, say, a psychogeriatric team who comes in, I feel it is really important that that incident be used as an educational tool. The staff know that resident. It is not just an abstract concept of depression, dementia, delirium or mental illness. They know Mrs Jones, so you can say: ‘You saw how she was. These features that she has mean that she is depressed.’ You can help them learn from that, and it is so much more meaningful for them. Particularly if you have people who have not got a high level of prior education, who are from a non-English-speaking background or who do not have an academic type of background—as a lot of the staff do not—then that makes it a lot easier and so much more understandable for them. Then, when they really understand that, you can generalise it out and refer to other residents and other incidents. I think that way learning can occur, but it has to be ongoing.

Senator McLUCAS—It was put to me the other day that one particular nursing home had a training program about people with dementia. I naturally assumed that they were simply talking about the care staff and the medical staff, but they went on to explain that the gardener participated and that it had been a good program. It became all of a sudden very clear that all of these people are going to come into contact with people with dementia and they all need to know.

Dr McKay—That is right. I think often programs are poorly targeted. It is across-the-board. There are some experiential programs. I have not been through them myself but I have got very good reports of their impact, especially across-the-board. There is a massive problem in terms of general practice training. How you target that, I am not sure. There have been proposals in the past about having a way of certifying GPs who go in to residential care. I know there are pluses and minuses to that, but at present there does seem to be an increasing problem with facilities accessing general practitioners at all. Those who do go in go from the excellent—the ones who go in there because they really care—to those who are not excellent, unfortunately. Our current system relies totally on having a good general practitioner going into the facilities, and it is the variability in that level of simple care which is making the biggest difference. There are major issues there. How to target the right people is, I think, a great challenge.

Senator McLUCAS—There is a practice incentive payment for GPs around mental health, I think.

Dr McKay—There is one, but there are hoops to jump through to get to it. I could be wrong, but I think it is mostly targeting those GPs who already have an interest and who already probably have some of those skills you would be hoping for anyway. So you are making better a small group who are already good, but you are not targeting those who are making the biggest impact on people and you are not targeting residential care. I am not sure of the current funding structure, but I know that, at least previously, the funding structure discouraged appropriate care, because there was a decreasing payment for each extra person who was seen in facilities. I am not sure if that is still the case.

Senator McLUCAS—It still is.

Senator KNOWLES—It is now part of the package that they can access more money to go into a nursing home.

Senator McLUCAS—I think we are talking about two different programs. There is the GP panels program, which is designed to encourage more general practitioners into residential aged care. My concern is that it will do what you are saying, Dr McKay—that is, reward those people who are currently doing it. I do not know that there will be any growth, but Senator Knowles will have a different view on that.

Senator KNOWLES—Not necessarily. I think it is too new to judge.

Senator McLUCAS—I was referring to the mental health PIP payment, and I do not understand the structure of the payment to know whether it can move into a residential aged care visit event.

Dr McKay—I do not know.

Senator FORSHAW—In the submission from the Mental Health Coordinating Council, you refer to two groupings: those with a long-term history of mental illness and those with late-onset mental illness. I understand what you are saying. I am interested to get an idea of the scope of this. Do you have any statistics or a feel for what proportion of people who go into, say, a nursing home facility then develop depression, for instance—put aside dementia; although I suppose that is perhaps the most common mental illness—as distinct from those who have already got a history, if you like? Presumably, if the resident has had some psychiatric treatment and their GP is aware of their history, the centre would be aware of that when the person comes in. That does not necessarily mean either that they are going to be welcome or that they are going to get the appropriate level of care, but I am thinking about this other category—the actual impact of being in the facility. What number are developing depression?

Ms MacLochlainn—That type of depression is called reactive depression and it is quite common. I will respond to this and then ask Dr McKay for his comments. In my experience, it is quite common for people to become anxious and depressed when there is any major change in their lives, and for people who are elderly and frail, this change is often seen as a loss. They have lost their home and they have lost their independence. This change comes on top of a whole lot of other losses.

Senator FORSHAW—Particularly if they have lost their partner or their spouse as well.

Ms MacLochlainn—Yes, if they have lost their partner or their home. They have probably also lost a lot of their friends, they have lost their health and they are becoming increasingly frail. They may have other disorders. They are probably not as agile as they were and they may have sensory impairments—their hearing and sight are going. They probably have conditions that are painful. All of these conditions on their own would predispose one to developing anxiety and depression, and when you get a whole lot of things like that and losses like that they compound upon each other, so I think that is a big risk.

Part of the training of staff is for them to recognise the burden and the impact of going into residential aged care and to be sensitive to that. They have to be supportive and provide a friendly, caring approach. I think also that some of the activities they have can help too. We were talking before about having your own things there, and I think that is a big help, as are things like helping people to use the phone if they have trouble with that—helping them to keep in touch with their families. All these things help. It is a huge area and if we are going to provide humane care it is an area that really needs to be addressed very seriously. It is an area that is really neglected because people are so concerned about ensuring that the aged are not getting pressure areas, that they are not having a fall and that the facilities are clean—and that is all really important, but this is important too.

Senator FORSHAW—We are not talking about a group of people—maybe you could comment on this—that necessarily need to be separated or kept in a different type of facility, such as you do with dementia patients. There are pros and cons on this, aren't there? There is the impact upon the other residents, but then there is also the recognition that this is something to be managed, as distinct from being cured. People still need the dignity of being able to live in a facility. The fact that they may have some depression is not a reason to think they are necessarily a threat or a danger to other residents.

Ms MacLochlainn—Because they have depression?

Senator FORSHAW—Yes.

Ms MacLochlainn—No.

Senator FORSHAW—Hopefully it can be managed.

Ms MacLochlainn—It can be managed, as I said, by a lot of the environmental factors and by the care that is provided. But I also think that part of the education of staff needs to be to help them not only to provide support to help minimise those reactions but also to identify when someone is becoming seriously depressed and needs some treatment for that as well as the support and care that I referred to before.

Senator FORSHAW—I hate to try and put figures on this, but is there an estimate of, maybe, how significant this is?

Dr McKay—There are numerous estimates. The paper which I will table, if you are happy with that, provides some estimates. It refers to aggregate housing, which I think is am American term for supported living, and they are talking about depressive symptoms in the order of five per cent. But, going into residential care, estimates range from 30 per cent to 75 per cent. It is not something that can be solved other than with a preventative approach, an across-industry approach and an across-health approach. It really is a striking difference from the rest of our society. A positive is that there is some work suggesting that there really are things that can be done to lower that incidence. Part of that is specialist services, but most of it is a preventative approach.

Ms Vaughan—With our residential services in Sydney, with the health funded model that we operate under, because we are an NGO and we are seen as being funded, if our residents need any support apart from what we actually provide—which is daily living skills training for persons in a house to help them get on with their day-to-day lives—we are unable to access any HACC services whatsoever. That limits what they can do, which also then may set us on the path of looking to put them into an aged care facility.

Dr McKay—The problem is that in the community—and there is evidence in America—those who need to receive Home Care type services have also themselves got a significantly raised rate of depression. So whereas the elderly in general do not have an increased rate of depression—and I could plug that residential care was not looked at with the mental health survey at all—people receiving care have a significantly raised rate of depression. If you want to look at groups at risk, look at residential care first. Second are those who are already receiving some sorts of support services in the community.

Senator FORSHAW—We might be able to hear from you again in another inquiry by this committee that is coming up. Thank you.

Senator MOORE—A free advertisement!

CHAIR—Thank you very much for your submissions and your attendance today.

Proceedings suspended from 2.57 p.m. to 3.12 p.m.

FULLER, Mr Gordon, Private capacity

WAY-FULLER, Mrs Margaret, Private capacity

WAY, Mr Cameron, Private capacity

FOY, Ms Gayl Irene, Private capacity

CHAIR—Welcome to the hearing today. Do you have any comments to make about the capacity in which you appear?

Ms Foy—I am the mother of a disabled daughter.

Mr Fuller—I am the stepfather of a disabled daughter.

Mrs Way-Fuller—I am the mother of a disabled, brain-injured daughter.

Mr Way—I am the brother of Fiona Way, a young person in a nursing home. I would like add to the *Hansard* the presence of Fiona Way as a witness, in the sense that we are her two guardians representing her.

CHAIR—Thank you. The committee prefers evidence to be given in public but evidence may also be taken in camera if such evidence is considered by you to be of a confidential nature. Witnesses are reminded that evidence given to the committee is protected by parliamentary privilege and that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee has before it your submissions and I now invite you to making an opening statement to be followed by questions from the committee.

Mr Way—I would like to make an opening statement on behalf of the three of us who work as a team. The first thing I would like to put on the record is that we do have concern that Fiona is still in a nursing home where we have had quite a good deal of abuse and, as recognised in our complaints, some degree of discrimination. So we just want to acknowledge that we have concern in speaking up for Fiona, and also for ourselves to some extent, but we are very happy to be here to speak plainly and openly. In opening, we would just like to state what we think our relevance is to the Senate inquiry. We know that it is a fairly long submission and I know that you have a lot of paperwork so let me just make it easy. Firstly, like Gayl, we represent a young person in a nursing home, and that is part of the issue. And my thanks go to the Democrats and Labor for helping get that on the agenda. It is very timely.

Secondly, what is exceptional about our situation is that we have three people to advocate on behalf of a person in an aged care facility. That could be an old person or a young person. We have had comments, for example, from experienced people working in the New South Wales Office of the Public Guardian that they have not seen a family who has had the capacity to exercise complaint processes at the level of thoroughness that we have been able to do. That has been a product of the fact that we have three people on our team. We have an architect in the aged care industry, someone who has been on the board of a nursing home and a professional psychologist. I have worked with people with challenging behaviours and intellectual disabilities in residential care services. In our case we have exercised all available complaints processes at state and Commonwealth levels about the serious situation of poor care and abuse. Two years after the completion of those processes our situation is actually worse than when we began. So we think our case is valuable in the sense that we are a rare test case of just how well the current system works.

Thirdly, through our family work, and primarily through Gordon here, we believe we have one of the most significant initiatives that hopefully will get off the ground in terms of private sector effort to establish more appropriate facilities for young people in nursing homes. We have stakeholders in major nursing home groups, the building industry, Rotary et cetera. Gordon is a good person to ask about that. As a family, we have also looked into the various models around the country, as best we can, to get an informed view of the economic models as well as the physical facilities that work. We are hoping you guys will get something to address the problem before we do, but we are doing pretty well.

I want to press upon the committee the level of harm to Fiona—that is Margaret's daughter, Gordon's daughter and my sister. There are two things I am going to say here which I have thought about very carefully and they are true and accurate perceptions. We have seen a deterioration in Fiona in the last 12 months. I have to say her level of emotional and psychological trauma over her four years in an aged care facility is more severe than the psychological and emotional trauma she has experienced as a consequence of a severe brain injury. That is the quality of the environment we have been dealing with.

In absolute terms, I have been struggling—and this does not come out in our submission—because every time we try and write about the process of watching her being broken down as a human being, and I am talking about mind and psychological entity, we just cannot find the words; they just do not come out. The only reference marker I can find is when I read about the quality of abuses, as recorded by the public media, in Abu Ghraib. I am absolutely clear that over the last four years the level of degradation psychologically, through processes of humiliation, fear and uncertainty, is at minimum equal to and most probably more severe than what I have seen presented about the suffering in Abu Ghraib.

You are welcome to question us on the processes by which that has been achieved. It is involved; it is a product of numerous actions and factors. It is all well-documented in our submission, if you have a chance to follow it up later. It is made particularly so in view of the duration of time that has elapsed. The failure of the complaint processes has certainly played a very big part in that being established in my sister. We fear losing her as an intact human being—not from her injuries but from her emotional experiences.

That is Fiona. Then there is us—a normal Australian family seeking to act in what we would say is a completely reasonable action: attempting to care for an injured next of kin in the current system. I am going to refer to the issue of the current civil environment that is established in which there is accountability on government, federal and state, more than on any other party, for the quality of that civil environment for families to be able to act reasonably. I have seen trends, through our experience of trying to advocate for Fiona, that I find disturbing in the culture of modern government and in the civil environment being created. It leads me to have concern that the situation for young people in nursing homes is likely, without intervention, to get far worse, not improve. I will give you three examples that explain why.

First, there is the environment for raising legitimate complaints. In our case, we explored the complaint processes at state and federal level. At federal level, there is the Department of Health and Ageing's Aged Care Complaints Resolution Scheme, which in our case actually did deliver a very good, appropriate and positive decision in our favour. It took about 12 months. The real critical failure was the failure of any effective action by the Aged Care Standards and Accreditation Agency. It is interesting to note that we had numerous parties at state and federal level warning us that that would happen, so the recognition that there is failure in the system is well noted even by public servants.

I would like to highlight in particular the consequences in our case. I live in regional New South Wales and have a partner who had been putting up with me being virtually absent for the last three years since Fiona's accident, and she had stood by famously. We have the additional stress of an older boy, her son, as well as our younger son. The older boy has severe behaviour problems. I would like to articulate briefly just how serious those behaviours are. He has had Asperger's, which we have found effective resolution for to a fair extent, but he also appears to have a second disorder, which can only be described as sociopathic. In his case, he has shown even more severely clear serial killer ideation, wanting to torture people and leave his name on their bodies. Furthermore, he has a hard-wired mind-set to gain a position of power and has a desire to kill all of humanity if he can. So it is a very disturbing situation. We are working to moderate that. We see it as sensible to seek intervention now rather than waiting until he is an adult. To our credit, the two of us have been finding successful intervention in his progress and development, thanks partly to some leading Australian research from the University of Newcastle in amino-acid testing. It is a very difficult and challenging situation.

I made the magnitude of that personal situation known to the complaints resolution scheme. I talked about my disability and writing disability in the demands. We had jumped through every single hoop up to that point in all the complaint processes and at that point my partner said simply, 'It's been three years, I need a break of a month, otherwise I don't think I'm going to last—you're going to lose me.' It was a very simple statement. So I asked the complaints resolution scheme, 'Can we please just have a delay of one month?' The response to that was: 'No. If you don't make a decision, we'll make a decision for your sister.' I had one-hour phone call that I can only describe as bullying—I was left absolutely physically shaken at the end of it. What was particular interesting about the situation is that they wanted us to progress to the next stage and to make a decision whether we would formally do so or not. I also advised them that our advisors were in conflict as to whether the problem that we had had been resolved effectively by the previous process. This is about what happens to people who are exercising complaints.

Most significantly of all I was acting in my legal responsibilities as a guardian for Fiona. A consequence of that is that while we were told there would only be one more process in a month it was three more processes. That relationship is now lost and I now have good reason to fear not only for my sister being harmed in a nursing home but also for my son, who is seven. The older brother at one stage indicated very clearly to me privately that if anyone is going to stop him from becoming master of the universe there is one person who must go and that is his younger brother. I live with that situation now in tandem with trying to protect my sister from loss of life and harm in a nursing home.

Why I feel that this is very important is that it is articulating what I particularly want to highlight about this situation. This is about the emerging culture of modern government that is very concerning in terms of an effective complaint system for what is going on in aged care nursing homes. The reason that they did not want to give an extension is that they needed to keep complaints within a limited time period to enable them to produce nice PDF documents for annual reports so that the department looks good. When they made that decision, they made a decision that the top priority is to serve the self-interest of government to look good and not the public that the complaint process exists for to protect people in nursing homes. That was a fundamental decision they made in that instance. We are bearing the consequences.

I noticed in the Health and Ageing submission that when they mention the complaints resolution scheme in their last paragraph they very proudly state that the average time taken by the scheme to resolve complaints in 2003-04 was 40.5 days, which is down from 40.8 days in 2002-03. I confess our family was probably entirely responsible for that 0.3 days. There is an issue here of what is real efficiency. The PDF document of the department looks like the department have achieved a wonderful efficiency, but in terms of the net commonwealth of this society they have not; they have caused a huge inefficiency, because we are bearing the cost of simply not having a break. My other points are much briefer than that, but thank you for listening to that.

The second example is access to information. We have completed our complaint; it has been upheld. It has binding consequences: the nursing home has to comply. The Department of Health and Ageing have a process of compliance, and they informed us they did not even bother to engage with us about compliance because it was so evident there was none. After this, while it went on to the Aged Care Standards and Accreditation Agency, we received no notification of the outcome of our complaint. There was just silence. Meanwhile, the nursing home has decided to seek to remove us as guardians, presenting that Fiona—and I must say this is completely inappropriately—needs to be permanently restrained. That involves the permanent life removal of her liberty as a citizen.

We understand that there are some issues of commercial sensitivity for facilities. We requested that if there is a need to preserve the confidentiality of the facility and commercial entities then that is fair enough, but that the government in that process has a responsibility to make known the behaviour of the nursing home to the New South Wales Guardianship Tribunal, which must preside over the challenge to our guardianship and be in a position to make an informed decision of whether we are adequate guardians or not. We thought that was critical information. We made FOI requests but we were denied access to all information—there was nothing. We have never actually learned what action has been taken about our complaint. We have no capacity to find access; we are left completely in the dark. In this regard I am very, very concerned because here we have a citizen who is being mistreated, who is at serious life risk in an aged care facility, and the way the current laws work that facility, after a successful complaint, has the right to be fully protected and the citizen who is at risk has no right of information. There is something very distorted about that; it is almost placing a corporate entity as a more fundamental citizen than an Australian citizen.

Thirdly, there are circles of responsibility. When we first began, when Fiona had her accident, as family members we sought to be responsive to this event and hence, in my understanding, responsible for her as next of kin. In New South Wales she completely failed to qualify for the compulsory green slip compensation scheme for people injured in motor accidents, so once again the family took up the responsibility of the failed compensation scheme. We then progressed to the public health system, which failed to recognise her concurrent relapse with chronic fatigue syndrome and could not keep her in the public system, so then we extended ourselves to take up the responsibility of the inadequate health system and tried to provide rehab.

We then moved to a nursing home, where there has been a problem with challenging behaviour. But they are so stressed they have no time to actually do appropriate monitoring and develop proper behaviour management, so we have stepped in to take up the responsibility for their incapacity to do so. Next, we began to uncover that there is a serious bully, described by RN workers as ‘sociopathic’ and ‘evil’ and who is responsible for deliberately obfuscating our attempted care, but the nursing home does not want to know about it, so we ended up taking up responsibility for the internal affairs that the nursing home cannot address and we tried to address that situation.

Then we engaged complaint processes which failed completely, so now we are trying to establish, make up for and be responsible for the lack of effective capacity of Commonwealth and state complaint processes. The police were involved; they had to withdraw because the two witnesses of serious physical assault and threatening her with the end of her life withdrew. So we are now faced with the responsibility of trying to find the evidence to act effectively to protect her. And because of the lack of appropriate facilities for young people, we are now expanding to meet that responsibility as well. We are the only party that has no authority and is totally unpaid, and in the end we are taking responsibility for everything. What concerns me about that story is that it is not a one-off; it is a consistent pattern of the modern civil environment currently created by the culture of government at both federal and state levels. That is, I think, a key point that the committee needs to have a clear focus on.

In particular, the civil environment that has been created by the two tiers of government—when it comes to dark corners like young people in nursing homes, an issue that everyone wants to not have to worry about—reduces the capacity for citizens to act reasonably and reduces the protection of citizens. Fiona is an Australian citizen and a New South Wales resident and has the right to be protected from harm, threat and danger, particularly when she is unable to defend herself. There needs to be effective accountability of government. The quality of the civil environment falls squarely upon federal and state governments.

To finish off, I would like to highlight something with Gayl and other representative young people in nursing homes. I understand the committee has had a number of submissions from peak bodies that necessarily represent the interests of bodies—whether they are peak bodies representing industrial groups, whether they are unions who represent the union movement and workers, or whether they are government departments trying to do the right thing by their elected governments. But, in the end, young people in nursing homes are Australian citizens. I want to highlight to the committee that I believe their witness is paramount. Their witness is more important and relevant to the committee than that of any of those other parties. They are citizens of a democratic country. This is our government and their government and there is failure here.

I have three last points. I would like to direct attention out from our traumatic experience of the last four years. The committee needs to look closely at the Commonwealth-state disability agreement and the fact that Labor state governments right across this country have signed off on that agreement twice now. They did not sign off to poke a stick at a few people with disability who need accommodation services but to provide comprehensive accommodation services. It was an agreement. There was a contract. I believe the committee needs to look very closely at the failure of what they signed to being responsible for.

At a Commonwealth level, prior to the last federal election—and this was deeply offensive to me—the Minister for Health and Ageing released a wonderful pamphlet saying there was no labour market crisis in aged care. I have not spoken to one person—a worker, a don, an advocate, a person in the public guardian’s office—who sees anything but a major labour market crisis in the aged care sector. I know it was based on some research done at Flinders University but it is a complete nonsense. That is a major deception of the electorate. If that becomes standard practice for governments—and I know governments do it at all levels—and if that becomes the level of deception that occurs before elections, I do not know how you can expect citizens to be honest with their tax. If I had had time to do a survey, I would have brought the results to show that there is a severe labour market shortage. As we have outlined in our submission, it is a major factor in the suffering going on in nursing homes.

In particular in this regard, I note that there was great fanfare about the billions of dollars saved by good economic management. I know a good portion of those billions of dollars were saved at the expense of the suffering of aged people that we see every time we go into that nursing home. There are not adequate staff numbers. They are one-third short of hands-on staff. I am saying that not as a union member, not as a facility but just as an observer and a member of the public. They are clearly one-third short of hands-on staff and that is half the problem.

Lastly, if the committee finds a significant discrepancy between those glossy PDF documents, submissions and annual reports and what you hear from young people in nursing homes, I hope you will be very thorough in trying to explain the difference, because there is a big gap between what really happens and what is being presented to the public. I want to thank Stu, the bus driver on my way down, and his wife, reported to be the ‘Perfumed Rottweiler’, who told us a wonderful story about granny snatching. They saved their aged person from a nursing home to take her home. I have kept hearing only negative stories from everyone I have engaged with over the last four years. That is how big the problem is.

Ms Foy—I would like to comment that I did put my first submission in and that I also put another submission in, on 17 December, stating that my daughter has been removed from a nursing home and put into a supported accommodation home. What I would like to say is that while she was in the nursing home she did not get appropriate care and she lost her dignity. I was frightened I was going to lose her. She was losing weight and she was severely depressed. It was awful. She hated going there. You would take her out and she would start crying when you took her back. There were people dying all around her. I was there one day when they pushed a body out past her. It is just not appropriate for young people. It really is not, and it has got to affect them ‘up here’.

What I would also like to say is that it has taken me 2½ years of constant battling with the government to get Amber out. She moved into the supported accommodation home on 11

December. We were worried about how she was going to settle in, but it did not even take a week. She is thriving. She has put on weight. In the nursing home she was not getting any physiotherapy and her muscles were wasting away. Now she is getting the therapy that she needs. She is going to the ATLAS program. The food is home cooked; it is not pureed so that it drips off a spoon. That is how she was getting her meals. She was put to bed, if I was not there, at half past one in the afternoon along with all of the elderly patients after lunch. She was then put back into bed when they had their tea at five o'clock. Now she does not have to go to bed if she does not want to. She is out through the day. Even at night there is no set time for her to go to bed. She lets them know when she wants to go to bed. She has got the choice of what she wants to eat or drink. She is just glowing; she really is. She moved in only in December and the difference in her is amazing. As I said, I thought I was going to lose her, she was losing so much weight.

Nursing homes are not appropriate for young people. The government have got to stop putting them in them. They have got to find appropriate accommodation for young people. It was a nightmare for her, but I had no choice. Six or seven years ago I had no choice, and being in the country did not help too. That was my only choice. You would go into the nursing home and she would be sitting in a dining room full of elderly dementia people with no staff around, no-one talking and no music on, just sitting and half hanging out of a water chair. You would have to go in and lift her up. She does not even sit in a water chair anymore. I would just like to say that I can see the difference from a personal point of view between what Amber was like in the nursing home and what she is like now. I am sure that if other young ones had the chance they would thrive like she is thriving now, instead of just deteriorating. It was just so depressing in the nursing home. It was depressing for us to go in to see her. Now we go over to the house where she is and she waves to us and dobs on the other clients if they are playing up. She is glowing. I think all young disabled people deserve that; I really do. They should not be shut away in a nursing home for the rest of their lives. I think I said in the submission that even criminals are eventually paroled. That is true. That is probably a bit blunt but it is true.

For these young people it is just not right—it really isn't. There needs to be more facilities for them and more supported accommodation homes for them. Once a week, because it was the nursing home's routine, for her bowels Amber was given some tablets. If they did not work she was given an enema. She was 30. This was because it saved the nursing staff time. On that particular day, this was the routine. Now that she is eating normal food and getting exercise, she does not need anything. It comes naturally now. They take her out in the bus. She loves going out in the bus, but she also likes going back to the house, which is great. You could see in that nursing home that she was miserable. She was not bathed every day and she was only allocated three nappies a day. Now she has a shower morning and night. She has her hair washed every day. It is just so different. The food she was given in the nursing home was pureed and I nearly lost her from aspiration pneumonia because it went down into her lungs.

Mr Way—Exactly the same!

Ms Foy—Yes. They just shovel it in. The staff do not have time. Of an afternoon in a nursing home—and I do not know about other people's experiences—the patients were put into bed after lunch and the staff would go and have lunch. If one of them happened to be on the toilet they would sit there pressing that buzzer until the staff had finished their lunch. Amber did not have the capacity to press a buzzer. On one night there—Amber had made friends with an elderly lady who was her adopted grandmother, as she called her—Amber was crying out at about three o’clock or four o’clock in the morning and nobody came down. She was in a separate wing and nobody came down. So this lady pressed the buzzer. Still nobody turned up to see what was wrong. Amber has epilepsy, so she could have been having a fit. She could have been choking on her vomit—who knows. Nobody turned up to find out. It is the whole atmosphere. I know some of the elderly people with dementia cannot help it. Amber is a young person and she made a bit of noise. They would tell her to shut up and be quiet. A few times even the nursing staff put her in the bedroom and shut the door because she was making too much noise for the elderly residents.

Mrs Way-Fuller—They would say she was naughty.

Ms Foy—And the elderly residents are who the nursing homes are for, not young ones.

Senator KNOWLES—I do not think anyone here would disagree with you that nursing homes are not for young people. They are not designed or accredited for young people. A failure of the system has led them to where they are. You beat the system and broke through. How did you manage eventually to get your daughter out of the nursing home and into supported accommodation? As Mr Way mentioned, the Commonwealth-state disability agreement provides money for the federal and state governments, but the responsibility at the end of the day is with the state governments to provide the accommodation. You broke through the system—well done!

Ms Foy—Maybe it was because I hassled Carmel Tebbutt so much. I just continually wrote to Carmel Tebbutt and John Brogden. As Amber was getting worse I would update them about it. Then John Brogden invited me down to parliament one day and he put a question to Bob Carr about Amber, but the question was not answered. I think it is about continually oiling the squeaking wheel. Sometimes you get discouraged, but you just have to get in there and do it. I think it was only two weeks before Amber moved into the house that I found out about it. They said that there was a position coming up. Firstly, they thought it would be down Taree way, but then they said there was one coming up at Lismore. I asked, ‘Can I check it out first?’ Everything was fine and I asked, ‘When can she move in?’ They said, ‘Before Christmas.’ My jaw hit the floor. I said, ‘You’re kidding.’ Apparently what they did was just rearrange things. There was a low-support person there and they moved him. He wanted to go to another low-support house that was closer to his parents’ place. That made room for Amber. Another young girl who was in the house went into hospital to have surgery but did not come out. I think you just have to keep bashing away.

Senator KNOWLES—Mr Way, you have gone through the complaints resolution process—I think your words were, ‘the failure of the system’—and the federal complaints resolution process. Given that Fiona ideally should not be in the nursing home to start with, I am not surprised that the complaints resolution process did not really meet your expectations. It is not their responsibility in the first instance. Mrs Foy has been a squeaky gate with the state government. Have you been an equally squeaky gate with the state government? Most of your contribution was about the federal process and the inadequacy of nursing homes to deal with young people. If you have been a squeaky gate, what has been your outcome?

Mr Way—The complaints resolution scheme did recognise our complaint and uphold it.

Senator KNOWLES—I realise that.

Mr Way—In particular, they recognised that aged care nursing homes have a responsibility to recognise, for example, guardians to enable some rehabilitation and to permit families to do case management and so forth. And that complaint was fully upheld. But, taking up Gayl's point, we have also been a pretty loud squeaky wheel. A very concerned member of staff rang up the aged care accreditation agency—that is what we can determine—alleging serious assault and abuse. The person there was off hours, on weekends, said, 'Oh, you mean Fiona and Leighton.' It was immediately recognised. That is the extent to which our case has become known in a wide range of circles. But we have also raised and explored the two complaint mechanisms in New South Wales: the Health Care Complaints Commission, which handles the conduct of professionals—and driving our situation at the nursing home is an RN who is basically a workplace bully; and, the health department's private health care branch, which deals with the quality of nursing homes. So I want to make it clear that we have exercised all three available complaint processes and had lengthy discussions with them. Where they all fall down is that none of them can get on the ground and actually interview staff, which is critical. The evidence of what was going on in this nursing home came from staff. The person creating this victimisation had complete control of the paperwork. They know how the aged care accreditation system works. They are expert at it.

As for Gayl's point about trying to find more appropriate accommodation, I would like to make two points. Firstly, neither we nor the people who put Fiona in the nursing home saw it as a permanent placement. Fiona simply needed a couple of years of high care so that we could progress her rehabilitation and get her well enough to get her out of there. Even the DON could see that she would be able to walk out within a year or two. The indications from rehab now are that, if we had not been obstructed, she would have been ready for in-community care a long time ago. But she is still being assessed as 'not available' because her needs are so high.

Very early in the piece, we applied to DADHC for SAS funding, which is what the state government expressed in terms of fulfilling accommodation services. I think 104 applications were granted and something like 36,000 applications were received. Those were the kinds of numbers. We do not have just young people in nursing homes; we also have a lot of young people being cared for by ageing residents out in the community, and their parents are getting older. It is like intellectual disabilities. The level of the problem is so high that it is just not being met. Now I make a habit of not ringing government departments once but ringing different branches all over the state. I sit up there getting a huge phone bill and just keep chipping away, like Ms Foy does, getting one opinion and then ringing another regional office and speaking to them, and then slowly piecing the situation together. You eventually get a breakthrough but it takes months.

We have been told once again, in terms of getting some increased services for older people, non-under 18, that if we get Fiona to a level where she does not require professional nursing care, which is the criteria, then sure. One regional manager on the north coast said, 'We've got a couple of openings up here. Do come back to me. You're obviously an active family. We'd certainly be interested in trying to support you and seeing what we can do.' It seems, certainly in the state government, that the focus—understandably, but sadly as well—is that there is a dramatic cut-off for anyone over the age of 18 who acquires a brain injury, because it is assumed that the legal compensation scheme will cover an adult who is injured, but there are injured people who are not covered. So a lot of the focus on funding in the New South Wales government is on children with intellectual disabilities.

Senator KNOWLES—How different would Fiona’s life be if she had had compensation? Bear in mind that obviously it would pay for a lot of things but, once again, it would not necessarily resolve the issue of accommodation availability.

Mr Way—If another driver were at fault and she were covered by third party insurance, the payout would be recognised in the millions, in terms of her lifetime injuries. Margaret or Gordon might want to comment on Senator Knowles’s question. I certainly think that with the level of friends we have, we could even have looked at becoming our own service provider and using established services in the community, such as nursing care and friends. The story would have been similar to what Gayl expressed: quality of life and the prospects for recovery would have been much more dramatic. I am not sure that I have answered your question.

Senator KNOWLES—Not really. I am trying to get to the bottom of whether the money would have actually made any difference to the accommodation prospects.

Mrs Way-Fuller—Yes, it would have.

Senator KNOWLES—Although you say that you possibly could have managed her at home.

Mrs Way-Fuller—But not personally, because we are just not capable now at our age—what with her weight and everything else. At the moment we are in a house with four levels. There is no way you could have a disabled person there. We would have had to find another home, and that is fine, and then we could have paid people to come in who actually understand a brain injured person, and there is all the rehabilitation. I would like you to look at this: this is where she is at now, and she should have been there two or more years ago, according to the neurophysio. My biggest gripe is that because of all the victimisation, being zonked out with all that respiridone and all that sort of stuff, they claimed that she had challenging behaviour. We had an independent person come in and check. People with disabilities—and this is in the submission—have said it was just normal, average. It is not. The only people she has problems with are those who harm her. Her emotional memory is extraordinary. That was explained to us by—I am not sure whether you understand the term—the brain injury unit people.

Very briefly, it means that, even though Fiona has reasonably good long-term memory, her comprehension is as good as yours and mine. Her short-term memory is very poor, so she cannot remember who has done what to her but, if somebody comes in—and there are some good people who do not have a problem with her at all—she sees the person and that person is kind. The next time that person comes in, she does not know who they are or where she has seen them, but she knows they are safe. Another person has harmed her, pushed her down and all sorts of things. If they come near, immediately she is so distressed and, because she is so disabled, she cannot defend herself. What makes me so angry is the way in which all these able-bodied people treat disabled people, who cannot defend themselves. It is atrocious and it is so traumatic to watch. Sorry—back to the question. I just get so angry and so traumatised when I see what goes on, and not just to Fiona. The way some of those elderly people are treated is absolutely disgraceful. It is inhumane. In this country, where we are supposed to be civilised, it is absolutely inhumane.

Senator KNOWLES—I do not want, as a consequence of today, and particularly with media present—

Mrs Way-Fuller—I was not aware that media were present.

Senator KNOWLES—Australia’s aged care facilities to be portrayed in a general sense as lacking in care and compassion, and it would be unfair. I am sure there are instances where people, such as you, can cite things that are happening that are far less than desirable.

Mrs Way-Fuller—Not just our family.

Senator KNOWLES—We do not want to try to portray the whole industry as being like that.

Mrs Way-Fuller—No, we are not doing that.

Senator KNOWLES—No, I am not suggesting you are. I am making it clear that some of the media have only just arrived.

Mrs Way-Fuller—I was not aware of them.

Senator KNOWLES—It is not a situation where the whole industry is crook.

Mr Fuller—I take up your point, Senator Knowles. A nursing home with a category 1 person, such as Fiona, gets paid $118 a day to look after her. The reality of the situation is that, to properly look after a young person who is brain-injured, who requires rehabilitation facilities—with equipment such as Fiona now has as a result of the Vincent Fairfax trust, local rotary and church donations—costs more like $360-odd a day, which would have to be allocated. That is, for specialised care persons, the equipment and the space that is required to store that equipment.

Senator KNOWLES—But it should not be in a nursing home.

Mr Fuller—I agree; it should not be in a nursing home.

Senator KNOWLES—That is the problem.

Mr Fuller—The point I am getting at is that there is nothing wrong with a nursing home per se; it is the fact that money that is available to look after the person in a nursing home is totally inadequate to allow the staff the time and the care that is required.

Senator KNOWLES—That is right, because it is not designed for that purpose.

Mr Fuller—It is not designed for it.

Senator KNOWLES—That is the whole point.

Mr Fuller—I have designed nursing homes and I have had a lot of experience with that and with dementia. You can design the best nursing home in the world and it still will not provide the facilities for that sort of person.

Senator KNOWLES—That is exactly right, and that is where the responsibility needs to come back to where they should be better.

Mr Fuller—Which is back to the states.

Mr Way—I feel I need to disagree to some extent. One of the things we raised in our submission is the concern about care of young persons in a nursing home, such as my sister. We are seeing the same systemic shortfalls in the aged care sector. The problem is that the level of staffing is not adequate. There have been other representations to the committee from some representatives of those workers, and we confirm the level of staffing with current funding is insufficient for the staff to provide adequate care so that the aged do not suffer. You see the suffering of the staff themselves, who are driven to a routine and are distressed by the fact that they are not able to provide appropriate care. I really have to disagree with you on that point.

Mrs Way-Fuller—Sometimes a photo is better than a thousand words. I was going to show that this is where she is now. I do not know whether you can see that photo. What happened to the girl in the photo before when she was medically restrained, unnecessarily? She could not do her physio. There are photographs of how she was. She would arrive there wet—and you mentioned only three pads. Now this is a young woman who worked in a hospital and who was very fastidious, so it was awful for her to be treated like that and left—and I do not say for one hour but for hours, absolutely hours—without anybody coming near her for what could be three, four or five hours. As well, just recently we took Fiona out on a Sunday night. I took in her clothing. Four days later I was there again and she was still in the same clothes. That is inappropriate—it is more than inappropriate. How you can explain that, I do not know. They said, ‘She has been showered this morning,’ but they were the same clothes and they were dirty. She is often left not only wet but also in faeces, and that is just not good enough.

The other thing that is important, apart from the pay, is education. The brain injury people went to educate them and they said, ‘We know all of this.’ Even they cannot get certain things through. It is not as if some of the elderly do not suffer similar things with loss of memory. It is very similar. If you look at Fiona, you are also looking at a lot of elderly people. We know of a number of instances where elderly people have also had to be put in hospital, where they should not have had to go, when things have gone wrong. I have to disagree with a lot. There are some beautiful people there—

Senator KNOWLES—I am not sure—you are addressing your comments to me—whether you are disagreeing with something I said. I am not sure.

Mrs Way-Fuller—I am disagreeing generally. Because we have been advocating, people hear about us and they show us and tell us of their own difficulties in a number of nursing homes. It is not just Fiona’s. That is what I am saying.

Senator KNOWLES—That is what I agreed with before. I said that there are certainly some shortcomings in some places. I have been in this game for 20 years and looking at nursing homes for that length of time, and I have to say that the quality of nursing homes in Australia now, compared to 20 or 30 years ago, is like chalk and cheese.

Mrs Way-Fuller—It well may be but—

Senator KNOWLES—But I think there are—and I agree with you—

Mrs Way-Fuller—In Western Australia where we looked, they had—

CHAIR—We will need to proceed with questions.

Mrs Way-Fuller—Absolutely.

Senator McLUCAS—Ms Foy, can I come back to where your daughter is now? Can you explain what the facility looks like and, if you know—you may not know this—can you tell us how it is funded and how the financial arrangements operate? Then, Mr Fuller, I might come to you if we have a moment to talk about those issues as well.

Ms Foy—The house that Amber is in now looks like a normal house in a normal street.

Senator McLUCAS—Has it been renovated?

Ms Foy—Yes it has been modified for wheelchairs and things like that. There are no signs up; you would not think that it was a home for the disabled. The department, DADHC, own and run the house. A percentage of Amber’s disability pension pays for her board and lodging, and what is left is for items that she needs. She is paying less than she did in the nursing home and she is getting more service.

Senator McLUCAS—Are there care providers who live on site?

Ms Foy—They do not live there but they are there 24/7.

Senator McLUCAS—On shift.

Ms Foy—Yes.

Senator McLUCAS—Who pays their salaries?

Ms Foy—DADHC.

Senator McLUCAS—How many people live in the residence?

Ms Foy—At the moment there are three boys and Amber, and I have heard that there is another girl going in.

Senator McLUCAS—So it is like a large family home?

Ms Foy—Yes, it is a big home. It is a homely home. If you are sitting in the lounge room or the kitchen, you can see what everybody else is doing—you are not shut off. When Amber was in the nursing home, she would be put in a room and she did not know what was going on around her. She likes to sit up at the kitchen bench now and watch all the others.

Senator McLUCAS—And see what is happening?

Ms Foy—Yes—and she loves it. As I said, it looks like a normal house in a normal street.

Senator McLUCAS—Thanks very much, Ms Foy. Mr Fuller, you have been thinking about how we can solve these problems. Would you like to share with us what you have done?

Mr Fuller—There is a transition stage which is of concern to me. For people like Fiona who are requiring a lot of rehabilitation you cannot just transfer them out of a nursing home into a four- or five-bedroom home without some specialised people coming in to do the necessary rehabilitation. The pilot scheme that I indicated in the original submission starts to look at a residential type of environment which provides those facilities and relaxation areas for young people so that they can actually live a life with some peer group people, enjoy the sort of music that they would like to hear, roll on the ground if they want to and generally have as good a time as they can.

I was interested in looking at the Carnegie project in Victoria. The MS Society has done that, and you would be well aware of that one. They only have funding for the transition stage and they do now know whether they will be getting any more money once it comes up to 2007. In my opinion that is a tragedy, because they do not know what the long-term plan is going to be. The Carrington Centennial Trust is putting up a proposal similar to the one we have put up—with a 20-bed care rehabilitation facility for young people in Camden.

We need to reassess through the state government the type of funding that is going to be allowed for these people. For every person who is in a nursing home at $118 a day there is an aged care person in a hospital who is costing probably $500 a day. If we can get these young people out of the nursing home into a facility and the government can give us the difference between the $118 and the $500 or whatever, we would be halfway there. This is the sort of thing that I want to see happen. I want to see the Motor Transport Authority and the insurance companies accept some responsibility for this, instead of looking at actuarial projections of millions of dollars to look after these people—because we will save millions of dollars this way. This is the sort of thing that I want to explore and investigate.

Senator McLUCAS—So it is a transition centre—for want of a better term—with the hope that eventually that young person will move into—

Mr Fuller—At the moment, I am moving people from Lorna Hodgkinson Sunshine Home—down syndrome—into four homes in the community, and we are modifying the homes in exactly the same way as Gayl was talking about.

Senator McLUCAS—Who owns those homes?

Mr Fuller—They have been bought by Lorna Hodgkinson Sunshine Home, because they are on a separate type of funding. They are on social type funding and not funded through the normal system of aged care.

Senator McLUCAS—You may not be able to answer this question. In other states the department of housing becomes involved. Are you aware that the department—

Mr Fuller—Margaret and I have been over to Western Australia. We have had a look at the facilities over there where the department of housing provides that. The brain injury unit works in close association with the department of housing on some of their facilities. They are trying to move everyone out of their site at Ryde and they have priority for that. I see it being a joint thing between the private sector and the government in the long run. I want to see the state government accountable for Julie Bishop’s $4.9 million which is being allocated, instead of not knowing where it is going.

Senator McLUCAS—Thank you all for your contribution.

Senator MOORE—I have one question: what kind of support for the families—all of you who are working through this—is available to you in any way? Is there any government sponsored support that you have received or any mutual support groups that you share? Or is it hit and miss?

Ms Foy—I have been getting a lot of support from the National Alliance of Young People in Nursing Homes in Victoria and People with Disability Australia here in Sydney.

Mrs Way-Fuller—The social worker at the brain injury unit at Ryde is excellent. In my previous work I also needed to have a supervisor or somebody to talk to about cases, so my daughter has taken on that role. They have both been absolutely wonderful.

Mr Fuller—We are lucky in some ways that we have very good support from our local Rotary club and from our church, both financially and physically with people. We have very strong support from people like Barry O’Farrell, Brendan Nelson and Judy Hopwood, who are very keen to see this situation find resolution.

CHAIR—Mr Fuller, we heard evidence from the New South Wales Council of Social Service earlier today. They are reluctant to support—in fact, I think they actually oppose—group homes or cluster housing. I take it from what you have said that you would not agree with that. Would you like to comment?

Mr Fuller—In this transitional stage, the ordinary home situation with a four- , five- or even six-bedroom home has to be designed specifically so that the people can have the right sort of rehabilitation facilities, which should include an activities room, very large storage areas and a staff facility where the staff can go out of the area, scream and come back smiling—that sort of thing. I am not saying you should not have that. I think the government’s philosophy is to have all these people out in the community, but I am scared that a lot of the people going out into the community will find it very difficult to assimilate, which is what the government is hoping for. That is why I think a transition home is best, not anything which is in any way institutional. I designed the first stand-alone dementia unit, which is a very homely environment for these people and they have a marvellous time there. They have their own gardens to walk in and that type of thing. So, when I talk about a transition facility, I am talking about something which is very domestic in scale.

CHAIR—Thank you all for your submissions and your presentation today.

Mr Fuller—Thank you for the opportunity.

[4.18 p.m.]

McRAE, Mrs Jackie, Private capacity

CHAIR—Welcome. Do you have any comments to make about the capacity in which you appear today?

Mrs McRae—I am here because my husband had a brain injury nearly three years ago.

CHAIR—The committee prefers evidence to be heard in public but evidence may also be taken in camera if such evidence is considered by you to be of a confidential nature. Witnesses are reminded that the evidence given to the committee is protected by parliamentary privilege and that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee has before it your submission, and I now invite you to make an opening statement to be followed by questions from the committee.

Mrs McRae—Thank you for inviting me here today. My submission goes into detail about why I believe a nursing home is inappropriate for my husband. I do not think that there is any disputing that a nursing home is not the right place for a young person to be. I would like to talk about what I want for my husband. I think that Todd is probably quite lucky in some regards in that his nursing home does not have some of the problems which I have heard about here today. I am sure that the staff generally are caring and compassionate and they do their best for Todd. It is just that there are not enough of them and they do not have the time to spend with him.

There also seems to be a culture that they do not believe that Todd has any potential. I believe that is crucial to Todd’s motivation and determination, which may be of benefit to him in having some recovery. Nurses think that they have seen it all and done it all before. A couple of them have said, ‘We’ve had people in here like this before and then they just wither up and die.’ If someone is just going to be sat in a room for years and years that is of course just what they will do.

With regard to what I want for Todd, I think that Todd deserves to be at home. I want to look after him. He wants to be there. It is very difficult trying to work out a system in which you just do not fit in anywhere, from the aged care assessment on. It was clear right back then that he needed more than even rehab could provide. He got six months of rehab, but six months is very early days for brain injury and recovery. Todd deserves the chance as an Australian, a taxpayer and a person to explore all possible avenues for some recovery. If people have cancer, they go through chemotherapy and have operations. They do not know if they are going to work or not. Does that stop people from spending money on it? No. I know that a lot of people have it. Cancer is more prevalent so there is more awareness and more money being directed into it, but brain injury is the most frightening thing that a family can ever have to go through.

You are dealing with so-called professionals. I know that they are very good in the jobs that they do and that they do help a lot of people, but there is a strict criterion to be met to even get rehab. Doesn’t everyone deserve a chance to get longer term rehab? I know that Victoria has a program called Slow to Recover, which is able to be accessed by people in nursing homes to allow them a chance to improve. Nobody can tell what that improvement is going to be or how far they are going to get. It depends on the injury, and I am sure it also depends on the person, given the determination that they had to start with, and the environment that they are placed in. If you are placed in an inappropriate environment you are not going to flourish. A plant will not live under a table with a cover over it.

I think that Todd deserves a chance to be able to come home. I want to be his main carer. You would have read in the submission that we have not been able to access any care, not even occasional temporary overnight care; we cannot get any. I believe that I am doing my bit as Todd’s wife to try to make things better for him. We have had overwhelming support from our local community and volunteers. Our local Rotary club has also been very supportive with some fundraising and providing things which we cannot get anywhere else. But why can’t I be given the chance to bring Todd home? Everyone says it is too hard, everyone says that I will not cope and everyone says that you cannot get the care. You cannot get the care, and it just seems so unfair that the work that I am doing just seems to have no flow-on effect. It is like I am out there on my own, although I know, having heard of other families, that I am not alone. I know that there are a lot of families out there trying to do their best for their people.

My husband is being denied the rights that he has as an Australian citizen to live where he wants to live and to have choices in his daily life. Todd’s being able to make some choices is probably quite a way off or, more to the point, our being able to interpret his choices is probably quite a way off. I think it is wrong that the DADHC does not want anything to do with him because he is in a nursing home—and because he is in a nursing home he cannot access any rehabilitation. It is just buck-passing. I have never been very politically involved but now I see that I need to jump in there boots and all, because this is happening to not just Todd but lots of people. Something has to change. The number of people suffering injuries will not decrease; it is increasing. It seems that there is no planning about what to do with all these people when their carers get too old to care for them.

I think there needs to be a combination of state and federal contributions to help people achieve the best possible outcomes. Flexibility is a key requirement of any funding that may be available in the future, because people want different things. You cannot say, ‘Okay because you’re 30 and you’re brain injured, and so are you, and so are you, we’ll put you all together.’ That may work for some but I am sure for a lot of people it will not work. People are still aware and want to choose who they live with and where they live.

Along with the support for accommodation I also want some rehabilitation for Todd. I am doing an awful lot with the helpers that we have. And with some of the fundraising moneys we are able to pay for a bit—but that has a limited life, as well. We cannot keep asking the same family, friends and community to keep digging into their pockets; other things happen in people’s lives.

CHAIR—We will ask you some questions and you can elaborate wherever you like.

Senator McLUCAS—Mrs McRae, will your home require modification for your husband?

Mrs McRae—That has been done.

Senator McLUCAS—Who funded that?

Mrs McRae—I did not have to pay anything. I was expecting to get a bill for 10 per cent, and I have not asked where the bill is. The work was done 18 months ago. Our house is all on one level. We had ramps built at the front and back doors, and we just ripped the shower screen out of the en suite. So it was not a big job.

Senator McLUCAS—When you said you expected to get a bill for 10 per cent, I did not follow you.

Mrs McRae—I do not quite know how things work, either.

Senator McLUCAS—It is probably better not to go there, then.

Mrs McRae—I do not know who the home modifications were funded by.

Senator McLUCAS—The state, probably. I hope they do not read this.

Mrs McRae—There was a mix-up. An application was made to do some minor modifications, and six months later, when I started chasing it up, I discovered that it had been faxed to the wrong number so they had never received it. I do not know whether they were trying to make up for someone's mistake—I did not ask and I do not care; that is done.

Senator McLUCAS—I am sorry that I have to go. Thank you for your submission and evidence.

Senator KNOWLES—Thank you, Mrs McRae, for your submission. It is yet another pretty awful story, to be quite frank. In looking at your correspondence, it is obviously as you describe in your oral submission. What have you done as a further follow-up from that correspondence? Obviously you are not the type of person to sit back saying, 'Oh well, that's it. They have said no.' Where have you gone since then?

Mrs McRae—After all of that I did think that I could not keep putting myself through that. I am trying to look after Todd and he is my main concern. I just had to give up on it for a while because I thought it was too depressing. I kept getting knock-back after knock-back. All the letters I got were passing the buck—it was someone else's responsibility. I was directed to call such and such and when I called that person I was told, 'No, don't call me, call someone else.' I was just sick of being on that roundabout for a while. So I had a bit of a break. I sent a couple of emails late last year to John Brogden and John Ryan, and I have actually got a meeting teed up with John Brogden in a few weeks time.

I suppose it was just before Christmas again that I thought, okay, it is time to get back on that wagon and get out there. Todd is not going to get home unless I do. I was trying to focus a bit more on the volunteers and the rehab side for a while. That seems to be going along reasonably well at the moment so now I am trying to direct a bit more energy into getting him home.

Senator KNOWLES—I have a practical question. You say that Todd is quite aware and it is therefore very concerning, in my opinion, that people talk about him in his presence as though he is not aware. In your submission you talk about the possibility of establishing communications with Todd. How have you gone about that and where are you with that at the moment?

Mrs McRae—That is the most important thing for Todd for his quality of life.

Senator KNOWLES—And for you too.

Mrs McRae—Yes. It seems that every specialist we go to see gives me a task. They say, ‘Okay, I have shown you how to do this. Now you can do that.’ I have probably had 10 or 20 people say, ‘Just do this once a day.’ If I had a list of all the things that I should be doing with Todd every single day—

Senator KNOWLES—You would need 48 hours.

Mrs McRae—Yes. So we are still working on that. Things with Todd have an impact on that as well. I do not think that he sleeps very well at the nursing home so he often spends most of the morning asleep. In between driving to the pool and him being asleep it is difficult. It is as though you have to wait for Todd to be fully awake and alert and then home in on that. But that might not be the most appropriate time for me to be doing that. There needs to be a lot more structure in his rehab in that regard. It also needs to come from other people expecting things of Todd, I think, and wanting an appropriate response from Todd. There are only a few people who ask Todd for that, so there is a way to go there yet. It is a shame for the Attendant Carer Program that that seems to be the crux of why he has been denied. It may be quite a difficult criterion to meet. It is already and I do not know when we will achieve that.

Senator KNOWLES—It is a pretty high high-jump bar, isn’t it?

Mrs McRae—Yes.

Senator MOORE—I have the same question I asked the other witnesses in terms of what support there is available for you and for your son. You mentioned your son a couple of times in the submission and this whole process will be impacting on him as well. From your point of view, what help and support have you received since 2002?

Mrs McRae—While Todd was in the brain injury unit the social worker there was very supportive. I still have regular contact with a social worker from Liverpool. It is a different social worker but I am very friendly with her. She rings me up.

Senator MOORE—Is she there for you or as part of the case management for Todd?

Mrs McRae—A bit of both. She is quite happy to listen to me if I need to talk about something. In saying that, when you need someone it is really hard to find someone who is available. By the time someone gets back to me, I am over that and onto something else. My son and I are supporting ourselves. In saying that, he does not want to see me crying anymore. He has had enough of that. And I do not want to be doing that either. So I try a bit of yoga and a bit of positive thinking. They do not always work either, but generally I have to try and be positive that things are going to change in some regard.

Senator MOORE—Is there any form of support network? As you have said, there are so many people going through this process across the country and in New South Wales. Is there any form of support network of people who have experienced what you are going through?

Mrs McRae—There are a couple of families who I have met—two particular families that I know of. They have their person at home, so they are quite busy. The Brain Injury Association of New South Wales do not advocate on a personal level, so as much as I have rung up a couple of times and whinged for an hour, they have not been able to give me any possible solutions. The National Brain Injury Foundation in Canberra has been fantastic. You do not know where you are going. I did not have a Canberra phonebook, so it is not like I just flipped through the phonebook and thought, 'I'll ring down there.' It is not until someone tells you about something that you find another way of getting some more support. The Young People in Nursing Homes Alliance in Melbourne is also helpful. I have been getting a bit more involved with that side of things in the last couple of months.

I suppose my family is sick of hearing about it. It is my life. They think that I should be living it another way. It is fine for them to say that but they are not in my shoes. They are coming around to the idea that I have never done what I was told anyway and I am not going to start now. They still ring up once a week and see how we are going and that sort of thing. Whenever my family have birthdays or things like that, they are always somewhere nice and cheap because I cannot afford to go out for dinner, and they are always somewhere that is wheelchair accessible so I can always bring Todd along. They are very understanding of the fact that Todd and I are a couple and we want to be included as such.

Senator MOORE—They are part of the process as well.

Mrs McRae—Yes.

Senator MOORE—I am particularly interested in the part of your submission that talks about the home in Canberra. You said you have been very impressed with that home but should you want to go and use it more with Todd you would be up for $3,000 a week because you are not an Australian Capital Territory citizen. That jumped off the page at me.

Mrs McRae—The first time Todd went down there I was pre-emptively told that this may be on the cards. He has only been there three times. The last time he was down there was August last year, and I had heard that this had been brought in. I do not know who is in charge—who is making the rules or whatever—but the last time that he went there that increase in cost was not passed on to us. Again, you do not ask any questions if you are not getting a big bill. I have not queried it.

Senator MOORE—We will follow it up, Mrs McRae, because it seems like a lot. It seems like an interstate thing, but you would also think that people would sit down with you and the family before you go somewhere so you know what is going to happen. It is just the way that paragraph is written that jumped off the page.

Mrs McRae—That would be a facility that, if I do manage to get Todd home, I would love to use. Of course, if it is at that cost, we will not be able to.

Senator MOORE—A similar facility in New South Wales, close to home, would be good.

Mrs McRae—Yes, but—

Senator MOORE—If there were one. It would be a very good resource to have something of that nature close to home.

Mrs McRae—Yes, definitely.

CHAIR—Thank you, Mrs McRae. Thank you for taking the time to make your submission and present it to us today. Personal experience is very valuable information for the committee in its deliberations.

Committee adjourned at 4.41 p.m.