
PRODUCTIVITY COMMISSION

DRAFT REPORT ON CARING FOR OLDER AUSTRALIANS

MR R. FITZGERALD, Presiding Commissioner
MS MACRI, Associate Commissioner

TRANSCRIPT OF PROCEEDINGS

AT CANBERRA ON WEDNESDAY, 6 APRIL 2011, AT 8.59 AM

Continued from 5/4/11

INDEX

MR FITZGERALD: Good morning, everybody. Welcome to the second day of the public hearings here in Canberra. I'm not quite sure what day it is in terms of the total public appearance. Nine or 10, or something like that. Anyway, welcome. If we could start with Carers Australia. If each of you could give your name and the organisation and the position in that organisation that you represent.

MS ROWELL (CA): I'm Christine Rowell. I'm a director on the board of Carers Australia and Carers New South Wales.

MS REID (CA): I'm Mary Reid. I'm acting CEO of Carers Australia.

MR MANN (CA): My name is Evan Mann. I'm policy manager for Carers Australia.

MR FITZGERALD: If you could just give us an opening statement. We received your submission. Thank you very much. We have had lots of discussions with various of your state colleagues and yourselves over time, so we have been grateful for that input. If you could just give us your opening comments, then we can have discussion.

MS REID (CA): Thank you, commissioner. I circulated our speaking notes yesterday. So you may actually have some indication of what we're going to say, but let's proceed. First of all, I just want to acknowledge the work done by Carers NSW in preparing the submission for Carers Australia, and I acknowledge the submissions from Carers WA and Carers Queensland who support the general line that we have taken in our submission.

First of all, if I just go straight in, Carers Australia welcomes the draft report Caring for Older Australians. We support the main direction for the reform recommended in the report and we believe that if this report is implemented older Australians and their carers would greatly benefit. In particular we support the proposed removal over time of quantity limitations on subsidised aged care services; that's relating to bed licences and care packages. This removal of those limitations implies the satisfying of unmet demand for aged care, and this of course is a very important aspect. It would also help create an environment which is more receptive to meeting the particular needs of individual users of aged care.

A simplified yet more comprehensive approach for informing older Australians and their carers about aged care services, assessment and entitlements implied by the proposed aged care gateway agency, which again is a very important element in this. A single updated aged care electronic record that promises to eliminate the need for repeated disclosure of medical history and personal circumstances, which is also important to us. A greater choice that would be available to older Australians and their carers in relation to providers, accommodation and various services. Greater choice would not only assist in securing the most appropriate care but also foster independence and help to secure more comfortable and enjoyable living arrangements for older people. So all those comments, we say, are very supportive of what the report is trying to do.

Some people may have difficulty with aspects of the commission's recommendations on paying for aged care, notably the proposed treatment of the family home in determining the level of co-contributions for approved care and support services, and we appreciate that this general subject must be faced. While some find it unpalatable, we say, yes, it must be faced, and we commend the commission for its creativity in seeking to find workable solutions in this area. There are several recommendations directly relevant to the role of carers, who of course we represent here at Carers Australia, which we strongly support, and in particular - and these are two things - the proposal to develop carer support centres and the proposed inclusion of carers assessment, which I'll come back to shortly.

Now I'm going to have to say something negative, I'm afraid. Having said all that, Carers Australia is disappointed that the draft report does not adequately recognise the role of carers in the aged care system, given that the report itself acknowledges that 80 per cent - and that is 80 per cent - of care in this area is provided by informal carers. We acknowledge some progress here in comparison with the issues paper, but the report still fails to appreciate carers as individuals in their own right, with their own needs, priorities and responsibilities. Carers are a unique stakeholder in aged care and they should not, as the report repeatedly states, be regarded as merely a subset of the workforce, a resource to be encouraged to stay in the sector.

Carers have much in common with consumers as well as workers in the aged care system, but they are distinct from both groups. Last year the Commonwealth parliament enacted the Carer Recognition Act 2010. I think it is important for us just to remind ourselves who a carer is. The act defines a carer as a person who provides personal care to another because that person has a disability, a medical condition (including a chronic illness), a mental illness or an age-related frailty. Persons paid under a contract or volunteer staff are explicitly excluded from this definition. This is certainly a definition that Carers Australia supports.

The act also sets down 10 key principles about how carers should be considered and treated by Commonwealth agencies and relevant organisations funded to support carers. These principles, along with relevant background, are included in our March 2011 submission to this inquiry, but allow me to read out two of them now, which obviously are very pertinent to this discussion this morning. The fifth one is, "Carers should be acknowledged as individuals with their own needs within and beyond the caring role." Number 7, "Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers." I don't believe that these and the other principles are as fully incorporated in the thinking and recommendations of the report as they should be. It is my hope that they will be in the commission's final report.

Let me now turn to some of the other points coming out of our submission. Firstly, carers as partners in care, which takes up this theme that we have just quoted from the act. Carers have care experience, skills and knowledge with regard to the care recipient, but they are often ignored in the process for assessing the care recipient. Carers must be included. They also need to know the outcomes of the process. Electronic records, consumer-directed care and arrangements for lodging complaints are important aspects of the proposed aged care system, carers should have a clear place in them. A carer identifier should be included in the proposed electronic care records, the opinions and preferences of carers should be taken into account in care planning, especially in situations where the carer plays a significant role in the care plan. Carers should also have the right to make complaints to the regulator.

Moving to the next point - which is quite closely related, I need to say - that's about carer assessment. In the report, assessment focuses on the carer's needs in fulfilling the carer role. That is important, but assessment should also address what the carer is willing to do and for how long. I need to note that in the report on disability, which we'll be discussing late this week, the assessment process under the NDIS focuses on what could reasonably and willingly be provided by unpaid family members and the community. That approach has much to commend it. Also, carers needs can be distinct from the those of the care recipient. Carers' access to services and support should not be dependent on the willingness of the care recipient to have contact with the aged care system, and we have many anecdotes and stories around that too.

Moving on to the role of carers in residential aged care. Caring relationships don't end when an older person enters residential care. It is important to realise that. A continuing caring relationship can be of great benefit to the older person and the carer. This is about maintaining family life. It can also benefit the residential facility. Carers need recognition and support to continue in their role, and that will of course differ from their role in the family home, while being distinct from that of the volunteer. Many families report feeling excluded or ignored by staff at residential accommodation. So it is quite a crucial point.

Paying for aged care and treatment of the family home. We are not opposed to the proposition that the value of the family home should be taken into account in some way in determining the level of co-contributions, but there must be adequate protections, first of all, for disabled children who are dependent on the older person and co-reside with them in the family home, and, secondly, for carers who reside in the family home because of the role and who in many instances have been unable to accumulate savings to buy their own home.

Finally, a very important point too, we have labelled it Conditions for Carers, using the workplace term. The report sees carers as part of the workforce and the system of aged care it envisages depends critically on informal care to provide the bulk of care, yet the report offers little to address the financial disadvantage that is a consequence of long-term caring. There is no consideration in the report of the adequacy of a carer's income. We believe there is a need for measures to boost the superannuation savings of carers. That again is a very important point, because the opportunity to accumulate superannuation is extremely limited when there's a long-term relationship.

Where does a carer turn if they are injured while caring? We believe there is a strong case for a system of injury compensation for carers. The report's recommendations to address unmet needs should allow some carers to get back into the workforce, but carers will continue to be at a disadvantage in workplaces that do not offer flexible hours. We believe the provisions of flexible working hours in the Fair Work Act 2009 should be amended to extend to all carers. I just say that some carers are included, but it's a very small number. What we're saying is all carers should be included in that definition.

My conclusion is that Carers Australia will look forward to an Australia in which caring for the elderly is a shared responsibility, in which all older Australians and their carers have access to the services and supports they need. The commission's report takes us, I believe, some way towards the goal. I trust that the comments I have made today, particularly in relation to the role and needs of carers in the aged care system, assist the commission in further progressing its thinking. Let me say that we would be pleased to continue dialogue obviously beyond the hearings today. Thank you.

MR FITZGERALD: Thank you very much. You raise a number of issues and you have also put forward a number - I think in the order of 30 - recommendations to us. So thanks for that. Sue might start with some comments, and then we'll go through a few of these issues.

MS MACRI: Just if we go to your first page and the proposal to develop care support centres, and you're obviously supporting that. There have been some concerns raised throughout the hearing, and I think it in fact was COTA yesterday that was concerned that this could cause subfragmentation of services between both the carer and the care recipient. Have you got any thoughts around that?

MS REID (CA): I'm not so sure I understand that question. There's a fragmentation between the services for the care recipient and the carer.

MS MACRI: If you get to the gateway and the care recipient is being assessed there and the carer, but also the care support centre is doing some assessment of the carer's needs as well, I mean, how do you see the - - -

MS REID (CA): We talk a lot about carers having a need to have their own assessment. Now, I would have thought that some assessment at least was going to be happening at the gateway level, particularly as we have such an emphasis on the total caring situation. You don't just take this one here and that one there in isolation, you have to see the whole thing together. But in looking at the situations together you still need to look at them separately as well. So I would think that the gateway itself would be starting to identify some issues there. But they'd need to be together. I don't see that it could function in a completely separate way.

MS MACRI: Would you see the care support centres being a part of the gateway?

MS REID (CA): Certainly working very closely, I would think, oh, yes. If not physically closely, then of course you would have very close referral and cross-referral arrangements, where whatever was identified at the first level would certainly be passed on to the support centre, yes.

MR FITZGERALD: The way we're envisaging it at the moment, you're right, is that the gateway will certainly look at the needs of the carer in association with the person that's ageing; and in relation to the disability report, similarly, through their particular "gateway" - they don't use that term - the assessment centre. Our understanding and what we have been proposing is that the care support centres, whoever operates them - carers would be able to access that directly in and of themselves, and that there would be, as there is now, some sort of basic assessment to determine as to whether people require emergency respite, peer support training, counselling, advocacy or whatever, those services that are finally delivered through those centres. We understand that's what you believe and your associations believe is the most appropriate mix. Is that correct?

MS REID (CA): Yes, we do, we certainly agree with that.

MR FITZGERALD: The second issue just there is, just to be absolutely clear, we are talking about carer support centres that would provide support and services for carers of people that are ageing, people with disabilities, people with mental health conditions and people that have chronic illnesses, so it's a combined service centre for carers.

MS REID (CA): So is that a development of your first thinking?

MR FITZGERALD: No, it's always been our thinking, but what has become very clear is that we have to make that explicit.

MS REID (CA): Yes. That's what I was going to say, if it could be explicit so it becomes a holistic approach, that is certainly what we would be supporting and I think we've said it in our submission.

MR FITZGERALD: We've had further discussions with the disability team and by June we will have confirmed a number of arrangements in relation to the intersection between the aged care and the disability systems. One of the things that is clear is that if we agree that there should be generic carer support services, then they should all be within the one program area at least.

MS REID (CA): Yes. So that you've got a streamlined approach and where there are overlaps and crossovers, well, it makes no sense to have separate infrastructures. You clearly do need a single one that covers all ground. Then of course with carers, they can be caring for various members of the family or friends. They could be caring for an older person but also a younger person, so you can't slice it down the middle and say you go here, you go there. So the whole caring role becomes the focus of the support centres.

MS MACRI: Some people will access the care support centre that don't need to access the gateway.

MS REID (CA): Yes, that could be right.

MR FITZGERALD: The issue in relation to the services that a care support centre will offer, I think we won't be all that prescriptive but we've identified a number of areas and I think you have too.

MS REID (CA): Yes.

MR FITZGERALD: I just want to clarify something that has come up in the hearings with your state based associations. Since the draft it's become very clear to us that we haven't done a good enough job of explaining what happens in relation to a whole range of services that affect people that are ageing but are not necessarily aged care services. There's two types. One is in relation to information, advice and advocacy, supported decision-making, if you want, and we continue to see that they would be provided by a range of peak bodies and other bodies such as Carers and would be funded separately for that. The second are programs which we can call social support programs and social inclusion programs which are a myriad of programs that exist in the community today.

Again, we're seeing those as being very important but not necessarily formal aged care services, in the same way we see that the carer associations or the peak bodies in the various states would be funded as they are now, separately, for a range of services including systemic and individual advocacy and so on and so forth. Then, in addition to that we would have these carer support centres that would actually deliver this range of services. So that the peak bodies exist as peak bodies with a range of services funded, but then the care centres, which could be run by the peak bodies or could be run by anybody else, would be a separate set of services.

MS REID (CA): So interesting that you develop that scenario because I think that could work very well, particularly if associations have the ability to auspice those centres. Another thought that came to me, and maybe we'll be touching on this later, in your report you talk about block funding and also the entitlement arrangement. So would you see those services being block funded, or would it be a hybrid of block and entitlement funding?

MR FITZGERALD: In terms of the issues about information, advice, advocacy, assistance to consumers, those organisations that provide that, often many of those peak bodies would continue to be bulk funded. In relation to the carer support centres, our view still is that we see that as block funded. Having said that, we've continued to ask and we ask you now whether there are elements of that that actually lend themselves to entitlement based funding?

The one that comes up obviously is respite. Just to flesh that out one bit further and then seek your opinion; there seems to be a view that planned respite should be provided based on assessment through the gateway and subject to entitlement. That is, somebody gets a piece of paper that says you can go to a provider and get, you know, two hours of respite per week, or whatever the figure is. The other view however is that emergency respite does not lend itself to that because it's unpredictable and would lend itself to a service, being the carer support centre, being block funded for the provision of that. The same would apply in relation to general advocacy, training, counselling, peer support, those sorts of areas, but we would seek your views on that.

MS REID (CA): I think you need to have basic block funding to make the service viable. I mean, this is a whole new world. We've really got to start a bit of blue sky here as to how this might work. Obviously there are ongoing infrastructure costs you simply have to guarantee. So block funding to a particular level would need to be there to make it work. I can see the possibility of, say, optional services coming in as an entitlement, and so you tailor the service to that need. Now, that makes it hard to plan but I can see that there's a sort of supply-demand thing that you should be able to manage.

The question would then be, well, to what extent. Is it 90 per cent of your budget or what is it that you'd expect to have guaranteed funding and then there would be an optional extra on top of that? I can see there would be room to do that but it would be very hard, when you got down to the nitty gritty, actually saying at what point do we draw the line here. It would be nice to say 100 per cent and the rest is added on top but in real terms I can see you'd be looking at a less than 100 per cent figure there. It's almost like a market driven thing, you know, how attracted would people be to buying your service. If your service is good, well, then they will come; if your service isn't good, they won't. So there's a lot to think about around that but I could certainly see a hybrid arrangement. What about you, Evan, do you have thoughts about that?

MR MANN (CA): I think the model addresses the concerns that we had expressed and also the states I think - Queensland and WA had expressed its concern. I think what you're offering removes much of the uncertainty for us and I can see how respite services are better suited to the entitlement approach - planned respite services. So I think there's a bit going for what you're proposing.

MR FITZGERALD: Just in relation to respite, we're struggling with one particular issue of respite, as you know because we've mentioned to you and your other associations, and that is, how do we achieve what everyone is asking for, and that is greater flexibility and accessibility to respite than we currently have? As you are aware, there have been propositions put by various groups and it's very strong in the disability report that in some way, shape or form the entitlement to planned respite and even emergency respite should almost be a cashed out entitlement, one that you can take and use and pay or supplement in some way - neighbours, non-resident relatives and other people like that.

So I wonder whether you have any views about respite generally and the best way to provide it? If I can just explain, nobody disagrees with the notion that we need greater flexibility but operationalising that is exceptionally difficult and tricky. Now, we are aware that it happens overseas but in the Australian context it is actually quite confronting as to how we achieve that. So just wondering what your views are, given that often respite is regarded as respite for the carer, although that's not universally agreed is the basis for approaching respite.

MS REID (CA): Well, I would make that point too, that it is meant to be respite for the carer but then how do you implement that in real terms? We'll come back to that. Then you have a question of, well, what is respite? We often talk about respite effect rather than respite itself because often there is a fairly standard view, "Oh, well, respite is when someone comes into your home to substitute for you, the carer, and you go off and do what you want to do," or alternatively the care recipient is taken away, presumably to a residential facility for a period of time, and so you are left to your own devices and that's your respite. There are all kinds of alternatives to this and I think that's where we've got to be a bit more creative and perhaps more complex as to how we actually consider what is respite and how do we manage it. So before I answer your question, I think it might be good if, Christine, you could just give us some personal view about that, because you've actually been in that situation, haven't you?

MS ROWELL (CA): I was smiling to myself when I heard you talk about the respite being for the care giver. My parents were at a situation where mum was with dementia and dad was her carer, and we as the family would encourage him and arrange for her to go to respite. It's funny when you think of it, because for mum it was disorientation and I'm not sure, but in a very short period of time it became a holiday in essence, because something was new for her, because she was in the position of just seeing things fairly consistently. For dad, even though he went to see her every day, he still had the break, as Mary said, just to lie in, or read the paper again, or whatever he wanted to do.

I think, for our organisation, for our country, to imagine that we can plan respite that will give the carer and those in need an equal position at the beginning is probably not possible, because if we spoke to mum about, "No, dad needs a break and so we'll take you to that nice place where you go to every week for singing," sort of thing, she of course couldn't connect the two and would say, "No, no, no." Somebody had to be able to - which is what we did - more or less say, "You stay there and you stay there and, now, this is where you'll be for three or four days, or three or four hours." I think the challenge for you is that there is no answer in respite that everyone's happy at the same time, but it's so important that both parties, when the support can be there through a care facility or somebody coming into the home, are given a chance for a break that they don't often know they need.

We, in our understanding of all of this - not we Carers Australia but we the community - can still facilitate that is available, both in the emergency need and just in the routine of life. I think that's where the carer person often has this integral role, which is to hold the one hand, hold the other hand, and talk to the facility or the carer who's coming in and say, "Now, it will be all right." But to just throw the needy person in, whatever their need is, sometimes can be very jarring without that link. It's not an easy position, but it's essential.

MS MACRI: That sort of takes me on to that, where you talk about the 10 key principles, and the seventh key principle, "Carers should be considered as partners with other care providers," and I just wonder if you can elaborate a little bit on that in terms of where you think we could improve, around the report, in that particular area. Because the relationship - and that comes back to your comments around, "You can't just fit things into boxes," it's around a whole lot of collaboration and partnerships, not just with families and carers but other organisations.

MS REID (CA): And health providers. This is the biggest challenge: when doctors and other health professionals are involved, very often it's seen as their professional ethic to deal just with their patient, who is the care recipient. If there's a mental health issue involved it becomes even more complex, because then there's privacy and confidentiality as well.

But what we are saying here and what the act is saying is that there needs to be, first of all, that carers have a role and it's an essential role; it's not something that sits to one side or is something to ignore, it's bringing the carer into the whole situation where treatment, diagnosis, and so on is actually happening, and recruiting the carer to be part of it. Because very often, if there's a treatment regime, the carer is expected to do it, and unless they're actually given a little bit of training or given the courtesy of explanation and discussion, sometimes the carer can go away and say, "Oh my god, how can I do this? What happens now? Nobody's helping me." So it becomes quite a stressful situation.

We're really starting from zero point here, to say the whole community needs to understand this and carers need to understand it too, because sometimes it can be that the carer is not assertive enough and particularly the older generation tend to stand back and say, "Well, the doctor knows these things and that's important." But to have everyone in this relationship becoming a lot more understanding and a lot more prepared to make it, not so much an equal arrangement, but certainly a more equal relationship than it is now. So this is a huge thing.

We can say it in one sentence here, but it's not just a matter of switching on; it's getting a whole education program, getting right into the medical and nursing schools, and understanding at that point even who carers are and how they need to be brought in as part of the team. Your question was, how do you improve your report: I think it's just understanding that issue and actually starting to - - -

MS MACRI: Where those partnerships emanate from.

MS REID (CA): Yes.

MR FITZGERALD: Just in relation to these recommendations you have around - I'm just trying to find the right words. You talk about it in terms of "pre-discharge" and you talk about it in terms of, effectively, the ongoing role of the carer, even when the person actually enters into a residential aged care facility. I understand that the caring role, in a sense, never stops.

MS REID (CA): That's correct.

MR FITZGERALD: And parents never stop parenting.

MS REID (CA): That's right.

MR FITZGERALD: But there is an issue about public support for that function, and with all of these the public support stops at some point. In carers, as I understand it and correct me if I'm wrong, the substantial carer benefits that come through the social security system stop after about a month or thereabouts.

MS REID (CA):   Six weeks after the care recipient dies or ceases to be - - -

MR FITZGERALD: Six weeks. So in a sense we've said, as a community, we recognise that six weeks after the active caring, the day-to-day caring, stops. I'm just wondering what you think we should say beyond that? Because whilst we absolutely recognise that people continue to visit and maintain close connectiveness with the relative when they're in residential aged care - in fact we encourage that, not discourage it; in fact it's not often enough in some facilities and for some people - I'm not quite sure where the public support should start and stop, and what are you actually suggesting in that? Because there has to be a cut-off in terms of public support.

MR MANN (CA):   Do you mean in terms of carer payment and advance?

MR FITZGERALD: I presume carers can continue to access your services and that of carer support services for a fair while to come, in terms of support and counselling, those sorts of things; that's not a significant issue. But beyond that, what are you actually suggesting?

MR MANN (CA):   I don't think we're talking here about an entitlement under social security law.

MR FITZGERALD: Sure.

MR MANN (CA):   In relation to residential facilities, there's just recognition within that facility to be able to access, to have space when you go there to meet with your family, to be able to cooperate with the managers of the facility, to be told about what's happening, and to have rights about, not just visiting, but to understand about what the regiment is for treatment of your mother or father, for example. I don't think we were going beyond that in terms of public support.

MS MACRI: No, because that's no different to any other person, family member. All those courtesies and all those inclusions should be occurring to anyone.

MR MANN (CA):   But we do hear it.

MS MACRI: It seems to me, with the carers, that if you've been feeding your husband, showering them, and doing all this at home, and then all of a sudden the person gets to the residential aged care facility and they're told that they can no longer do that or have that responsibility, there's a real disconnect and a grieving, I would think, for the carer.

MS REID (CA): Absolutely, yes.

MS MACRI: It would seem to me, in essence, that's what the report, your recommendations, are talking about, in terms of that continued involvement and inclusion.

MS REID (CA): Yes, and I think what we're saying is that, "Don't shut them out." Yes, and there is that extreme of, "You're not needed, because we're doing this." I don't know how many facilities these days would get away with that but, not so far in the past, it could have happened.

MS REID (CA): One would hope not.

MS MACRI: There are certainly more enlightened facilities now where all family members are welcomed as part of the remote family, in a way. Once you have the facility there, it's like your family has just moved to another place, but you need to be able to integrate that into your family life. I was just going to again refer to Christine's experience where you used to visit twice a day and you took the dogs. So that was a lovely story as well.

MS ROWELL (CA): Mum and dad wanted to stay together and have access to their dog, but with mum with high level need dementia and dad was low level need, we couldn't find anywhere that they could be together and eventually did and I was able to take my dogs as well in in the morning and leave them with them for an hour or two. That didn't only mean the world to them, but it actually meant to the world to all the other residents because they would see them coming along. My brother-in-law has cerebral palsy and in the centre that he's in, there's canine support there and it's just amazing what a difference it makes to the saneness of a day when a little four-legged thing walks down the hall, and that's all it often did. So those sorts of allowances from the professional team of the carer and family support make the difference between boredom and some smiles in a day.

MR FITZGERALD: Can I just clarify this - and again I'm sure it's in the full recommendation submission you've given us - but you say here in recommendation 9, "The commission should make a recommendation or proposal to ensure that carers and care relationships are supported in residential aged care facilities." Then you have recommendation 10, which says, "The commission should recommend support for carers' access to service and supports beyond the end of the caring role." I can understand that 9 deals with that issue about culture within the service itself, but then what is 10 aiming to achieve?

MS REID (CA): It is saying that caring doesn't stop once the person enters a facility. I think the other commissioner there was saying that there is a grieving period. Even if the facility is welcoming, there is still a grieving period because the carer has to still go home and sleep in the bed on their own or whatever. So there is that time of needing still that support of transition. We're not talking about money per se, if that's what you're saying. We're not looking at the carer - - -

MR FITZGERALD: If I can just push it a bit, what is it? In other words, when you say "should recommend support", is that simply access to, for example, the support that we're talking about through the carer support centres.

MS REID (CA): Yes, it is. So another assessment just reviewing the change of circumstance in the life cycle and what is appropriate at this point. That's what we're saying. We're not making a statement about income. It's about support.

MR FITZGERALD: It's that. Okay.

MR MANN (CA): It's not about income support. I think we should also be mindful that a carer who has tended to their parents for many, many years, the parent dies and they're left with not much. This goes back to the financial disadvantage issue. So they can pick that up. We can discuss that later, but that also is implicit in what we're saying in our recommendation.

MS MACRI: Just again in your paper you talk about it's important in the assessment of the carer in terms of what they're willing to do and for how long. I would guess too that it's important, not only that, but really about whether the carer has the capacity to deliver the care. I wonder what your thoughts are around that because I would have thought it's not just about what they're willing to do and for how long, but some people feel absolutely obligated beyond what is reasonable.

MS REID (CA): That opens up a whole web of complexities around family relationships too. In other submissions to other inquiries, we've talked about carer preparedness and that implies capacity, as well as skill, knowledge, expertise in what is expected of them, but once you go beyond that understanding of what capacity the carer has, if there's some assessment being done, then it may come out of that assessment that actually the carer isn't in the best position and so then the question is who can be, and that's when you start to look at other family relationships and it gets very, very difficult, because very often in a family a person either comes forward or emerges - it's almost an osmosis kind of thing - as the one responsible and the rest of the family are saying, "You do it. You do it," and walk away. So if there's some assessment that says, "This carer isn't quite ready or able," for all kinds of reasons, then what is the solution? I don't know if you can go back to the family and say, "What about you?" This is very, very complex.

MS MACRI: The solution I would suggest then is the gateway and then it's around that care coordination and case management and it would be the gateway and through that assessment process that it would be deemed to look at what is the best and most appropriate environment for the care recipient. You would have to take it on - - -

MS REID (CA): It's a very complex set of relationships, yes.

MS MACRI: Just taking it on from that then and talking about people being injured while caring, which I think is a really important one and it has come up a number of times from various advocacy groups as well as your own organisation, do you have any stats or anything around the injury rates of carers or - - -

MS REID (CA): Not at the national level. I think that Carers WA have done quite a thorough study of that, possibly Queensland as well, but we'd have to come back to you on that one. I can't give you those sort of figures.

MS MACRI: If you've got any sort of - - -

MS REID (CA): Anecdotally we could certainly give you many stories, but I'm not sure that we can quickly give you actual numbers. But, yes, it is a significant issue.

MS MACRI: It is and around that compensation for carers and - - -

MS REID (CA): But really part of the problem there is prevention. It could just be a simple course in manual handling and lifting is what is needed and maybe a bit of first aid and CPR, that sort of stuff. It could be as simple as that.

MS MACRI: Or even a more appropriate bed, a high-low bed and - - -

MS REID (CA): A whole range of things.

MS MACRI: - - - a whole range of aids and assistive devices.

MS REID (CA): That's right. That then gets into the equipment and aids of course. But if we can have an emphasis on the preventative side of it, rather than what do you do when it happens, then it's certainly a better approach.

MS MACRI: Which would all be part of that carer assessment again.

MR FITZGERALD: That brings us onto this general issue about financial disadvantage and your recommendation 23 that says we should make recommendations about addressing the significant financial disadvantage.

MS MACRI: Yes.

MR FITZGERALD: I just want to explore that if I can. In a sense the government would say that those are recognised in part by the carer benefits and allowances that are currently provided, the adequacy of which I'm sure you will debate. In a sense it's outside of our province to deal with those. I know the campaigns that Carers Australia and others have run over a long period of time around the adequacy of those benefits. Nevertheless, in a sense that's the instrument by which the governments have said, "We recognise these costs." So I'm just wondering over and above that, again what do you think we should be recognising? You've got the superannuation, which we understand, and a few other things, but - - -

MS REID (CA): Sorry, before we move off that, can I just say that the level of the carer payment, which is the basic income support measure, is set at the same as the aged pension. There is no particular indication of caring as a separate occupation or use of time, except that there are a couple of additional supplementary payments that are made during the year, twice a year. So let's not see those payments or the carer allowance either as real compensation for the cost of caring. The carer payment is simply an income support mechanism. The carer allowance is a very tiny amount, it's $50 a week, to offset some of the costs. So even in the literature you read from government and Centrelink, it does not at any time claim that this is to cover the costs. So there clearly is an unspoken recognition that this is probably not adequate because there are many situations where carers are spending a lot of money on medications, electricity, transport, a whole range of things that are way over and above what their payments would allow.

So I guess what we're saying is there's that as a major issue anyway and I take your point that government is probably not quite ready to reopen all of that discussion because - - -

MR FITZGERALD: I'm not saying that, I'm simply saying we're probably not ready.

MS REID (CA): Yes, but of course the pension review that took place a year or so ago, that canvassed that and so that's pretty much a closed book right now. But the other broader question of financial disadvantage comes back to the fact that many carers, being out of the workforce for a very long time, do not have access to employer-funded superannuation, and so heading down the track of an age pension in their later years, there is no other possibility, unless they have other means. But we know from ABS statistics that a very large number of carers are in that lowest percentile of income. So the picture you have is of people struggling to get by during their working years but then when retirement age for others comes, they just have to keep on going. Now, of course they've got the option of staying with carer payments or going on to the age pension. There's still some capacity to retain a little bit extra from that. But they're not looking at a life of luxury at 65, 67.

MR FITZGERALD: Have you got specific recommendations in relation to this financial disadvantage or is just a general - - -

MS REID (CA): We are talking about - - -

MR FITZGERALD: We've got the super in your recommendation - - -

MR MANN (CA): There are only three, I think. We acknowledge of course - because of the recommendations in this and the disability report - it will be possible for more carers to take up work, so far as you meet unmet need and so on, but in the specific recommendations, there's one about superannuation.

MR FITZGERALD: Yes, got that.

MR MANN (CA): Compensation is one really; that allows you, if you are injured and have a disability later in life, and around the family home, the comments about if you do start including the family home in the assessment of what is required in the case of contribution, the carer is in a particularly difficult situation if they live in the family home and they have been there for years. I think they're the only three specific recommendations we made.

MR FITZGERALD: Yes, and we've got those. Thanks for that. I'm not indicating by my question that we don't recognise the costs of caring. They're very significant in many families. It's just again trying to make sure that we're looking at the totality of support by government and then over and above that, what's necessary, if anything. Can I just move briefly to the issue of aids and equipment. Now, it may sound like a strange one to choose but we've become very much aware of this issue, especially with new, assistive and adaptive technologies coming in to the market. We are sort of thinking about how to deal with this. In the draft report we didn't really deal with aids and equipment and assistive technology, so we want to deal with that. You will be aware that people have criticised us heavily for not having dealt with that adequately. Your recommendation 26 to us in your supplementary 1 talks about that.

MS REID (CA): Yes.

MR FITZGERALD: So I'm just wondering whether you could just tell us a little bit about any concrete ideas, if you have any, about how we address the issue of aids and equipment.

MS REID (CA): I guess the first thing is that you need to be more expansive about how useful how all of these aids and equipment can be. It's going back to our earlier point about making life a little easier for the carer and therefore preventing injury later on or even earlier. Injury can happen quite quickly; it doesn't have to be over a period of time. There are so many aids that are coming on to the market now. There's the monitoring of heartbeats and so on; there's aids to prevent falls and so on. So there's a whole lot of things that just need to be explored and to make them more accessible to people because that's the other thing: often these bits of equipment are pretty expensive or hard to come by or not trustworthy. How do we actually have a system of endorsing products and so on so that you know you're getting good stuff and value for money? There's a whole sort of industry out there that I guess we all just need to have a look at and say should this be supported? How much should the Commonwealth be taking on versus the states, because I know the state government does subsidise them to some extent, but depending on where you live, it may be this or it may be that or whatever. There's a lot of disparate programs out there that just aren't connected, so I think there is some further work to be done. Again, we can talk to you separately about that.

MS MACRI: But I think the gateway is going to alleviate some of that around - especially if you come through - and I'd suggest a lot of people coming through would be either on that HACC-related service or a CACP or an EACH or an EACHD, so again coming through the gateway and having that good coordination and case management, one would hope that the case manager, in looking at the client's needs, would not be just looking at whether they need a shower or Meals on Wheels or respite care but looking at the whole environment in terms of how that person can be cared for safely within that environment and how the carer can provide that care safely.

MS REID (CA):   Good. But then you would still have to have access to this equipment and some funding to support it, so that's part of it too.

MR FITZGERALD: One of the issues that we will be trying to deal with - there seems to be an awful lot - is the issue of equipment and assistive technologies, but we have to do this in conjunction with the disability system.

MS REID (CA):   Yes.

MR FITZGERALD: You may or may not be aware there's been quite a concerted campaign, an effective campaign by the vision impairment groups around Australia, so they have presented at just about every hearing, the various groups that support those that are legally blind, but they raise the interesting question there that of course a person with a disability, a vision impairment, requires aids irrespective of age, so there's an issue about that.

MS REID (CA):   Sure, yes.

MR FITZGERALD: The second thing is who actually provides the equipment, and of course they have many associations which provide equipment, but then the third issue is about how do you charge for it? This is quite complex because a lot of the aids and equipment can be purchased over the counter at the local pharmacy and yet on the other hand, some are very specialist, very expensive equipment, some is subsidised and some is not subsidised. So we're just trying to get a handle around that and it is an issue for the disability system as well. We are looking at that issue, so if you have any clever ideas, we'd be grateful about that.

MR MANN (CA):   I have one comment and it's actually made in our submission. It's in relation to aids and appliances, the very high level of private expenditure as opposed to public expenditure. I'm sure that's not a brash policy decision - that it's just willy-nilly, it's happened - compared with pharmaceuticals and so on. There's a very high proportion of money spent by the private person rather than government.

MR FITZGERALD: That's true.

MR MANN (CA):   That doesn't seem to me to be defensible really. I can't see what that is that way.

MR FITZGERALD: It's also true that a very large number of charitable not-for-profits receive very substantial donations explicitly to provide support for people with disabilities, for example, guide dogs and so on and so forth. So the history of the provision of aids is quite different to the history of pharmaceuticals.

MS REID (CA):   Yes.

MR FITZGERALD: It's an interesting landscape that we're in now. Where do we go to from here is the question.

MS ROWELL (CA):   I think looking at expanding reuse and recycling is a very important issue to consider. We couldn't give away the things that my parents had by way of making their elder years comfortable when they died. Nobody wanted it. We rang a few departments. One of the Smoky Dawson chair things my mother-in-law had was a government-provided chair and they just told us, "No, we don't take them back, it's too difficult." I know it's not simple, but I think if there can be some investigation into that, because a lot of them are not used for a long time and as long as they're clean and functional most older people are just so relieved to get that back pressure changed or whatever, and yet at the end of their use, because the people who are using them have gone, there wasn't an option other than discard, or giveaway to somebody else, which we tried to do, but that would be a huge cost saved because there's a lot of money in getting those out.

MR FITZGERALD: Are there any other final questions, Sue, from you?

MS MACRI: No, not from me. It's been really useful, yes.

MR FITZGERALD: Any final comments that any of you would like to make?

MS REID (CA): Well, only final comment being thank you for the opportunity of having this discussion, and in fact having a whole hour is really quite a privilege and we appreciate that. Now, if there are particular issues that we can come back with, we just do a separate submission to you?

MR FITZGERALD: Yes, exactly. At this stage you can just simply send us an email - within quotes. We're happy to receive anything at this stage.

MS REID (CA): So when is your final report due to be released?

MR FITZGERALD: It will go to the government at the end of June and, unlike the draft, the government releases the final report and they have a time limit within which they have to do so. I would anticipate a relatively early release by government, not necessarily an early response by government.

MS REID (CA): No, but an early release. Thank you very much.

MR FITZGERALD: Good, thank you.

MR FITZGERALD: Could we have the ANF, please - the Australian Nursing Federation. Thanks very much. Welcome. If you could individually give your name and the organisation and the position within that organisation that you represent for the record.

MS MIRAGAYA (ANF): I'm Jenny Miragaya; Australian Nursing Federation, ACT branch, branch secretary.

MRS CLARK: I'm Brenda Clark. I'm a resident of an aged care facility in the ACT.

MS WILLIS (ANF): Maureen Willis; registered nurse and just retired from aged care after 35 years.

MS ROSBOROUGH (ANF): Athalene Rosborough; branch president, ANF, ACT branch.

MR FITZGERALD: Thanks very much. As you're aware we've had lots of submissions and presentations from your sister organisations throughout the states and territory and we've got a few more to go yet in Brisbane and Darwin and we welcome that, but we're very happy to have you. We also have a reasonably substantial submission from your, I think, Australian body as well. So if you'd like to make your presentation and hopefully have some time for questions as well.

MS MIRAGAYA (ANF): The Australian Nursing Federation is the largest organisation representing nurses, midwives and assistants in nursing in Australia. We represent over 200,000 nurses, midwives and assistants in nursing, however titled, within Australia from both an industrial and professional perspective. The ACT branch of the ANF is a small branch within this federation but represents the majority views of nurses, midwives and assistants in nursing in the ACT. I do not propose to reiterate the submissions already submitted by the federal and larger state branches of the federation but do need to place on record the unwavering support of the ACT branch and its members for the principles outlined in those submissions and the tenets espoused through the ANF's Because We Care campaign.

The ACT ANF and its members consider that there needs to be an ongoing commitment to adequately fund the provision of aged care within Australia so that the right balance of skills and nursing hours are available to provide quality care for every resident or aged care consumer. The wages gap between the pay rates available within the aged care sector and that available within the acute care sector is to be addressed and that those nurses and care workers working within the aged care sector are paid fairly for the valuable care that they provide. The professional skills of assistants in nursing and care staff is recognised and remunerated appropriately and that residents and aged care consumers can be protected and assured of a consistent quality of care provision through a national licensing system for this category of worker. Taxpayer funding is transparently used to fund nursing and personal care for each resident and aged care consumer.

The ACT ANF understands that the ACT government does not provide residential aged care services within the ACT. The ACT ANF further understands that other than the provision of acute care of the elderly services in ward 11A at the Canberra Hospital and the funding to the Salvation Army in respect of respite and convalescent services at Burrangiri, there are no publicly provided residential aged care services available within the territory. All residential aged care services are provided within the for-profit or not-for-profit sectors within the territory with the Commonwealth responsible for the majority of funding.

Rather than represent the submissions already provided to the commission the ACT ANF has asked a representative sample of members currently working in or recently retired from the residential aged care sector to provide you with both some positive and negative insights into the provision of aged care services within the ACT. I have also sought the assistance of the ACT ANF branch president Ms Athalene Rosborough because of her expertise within the area and her knowledge of the ACAP processes so that the commission can more readily explore how aged care provision is managed within the territory.

Many of the concerns which affect the satisfactory delivery of aged care services within the territory are: adequate and inadequate staffing levels and their effect on care delivery; appropriate or inappropriate skills mix and its effect on care delivery; the reduction in the availability of registered nurses and its effect on care delivery; a real or perceived cost cutting culture and its effect on care delivery; excessive workloads and their effect on care delivery and work-life balance and job satisfaction. Ms Rosborough, Ms Willis, Mrs Clark and I will be happy to answer questions from the commission in respect of these matters.

I need to also place on the record that Mrs Clark is not a nurse, she's not a member of the ANF, she is formerly a teacher and she actually contacted the ANF when the Because We Care campaign first started because she heard the former federal secretary Ged Kearney and her presentation at the National Press Club. She's been very supportive of the ANF and the Because We Care campaign over the last two years. Thank you.

MS WILLIS (ANF): I also neglected to say I'm a member of the ANF. I have worked in aged care for approximately 35 years and there have been many changes over the years but I cannot say that they have all been to the benefit of the elderly residents. My mother is in an aged care facility so I'm also a consumer of - and I'm not always happy with what transpires but there's not much I can do about it. I have worked in one facility for 20 years and another for eight and they certainly have cut down on registered nurses. Where I worked previously they do not have a registered nurse on their shift. For night shift they have a certificate III carer.

MS MACRI: Is that a high-care facility or a low-care - - -

MS WILLIS (ANF):   It's a low-care facility with high-care residents and a dementia area so they do have challenging behaviours. Certificate IIIs don't always have education. They're supposed to, but they don't. They have them giving out S8s, carrying drug keys, which they are not supposed to do. We don't have the RNs to do that. You need to have your chain, you need to have your carers, they're very, very valued and they do really look after them but they need the education. So many of them can't even make a bed. Also today there is a high percentage of employees in aged care facilities that have difficulty with the language.

MS MACRI: It's come up consistently right across Australia is the quality of the RTOs and people going through the RTOs for their certificate III and certificate aged care, the cert IV. I would be interested in your experiences in the ACT if they mirror what other states and territories are currently experiencing. We're hearing that people that go through the TAFE system or the better RTOs come out quite work prepared and then there is the other sort of quick fix "be a nurse in seven days" and people come out quite unprepared. What are the experiences around the quality of the education for these people?

MS WILLIS (ANF):   I definitely agree with that statement. The longer the training, the more efficient they come out. The cert IVs through the TAFE they do 12 months and they certainly are better educated and more efficient and have a better understanding.

MS MIRAGAYA (ANF):   I think this is one of the reasons we would actually like a national licensing system so that you had consistency of qualification and standard. I am also a consumer. I have an 88-year-old father who went into care last year. But the facility that he is in in the ACT makes sure that there is a registered nurse on every shift. Now, I might like more than one registered nurse on every shift, but at least I am assured that there is a registered nurse on every shift within that facility. They have quite a percentage of enrolled nurses and every one of their carers - and they're not called assistants in nursing in this facility, they're called personal care assistants - but every one of them must have a certificate III in aged care that is appropriate for the job.

So I can be assured that my father, who is 88 and would much rather be at home - he didn't make his decision to go into a residential aged care facility on an accommodation choice. His choice is to be at home. But even with the support of DVA and assistance and living with my brother and my sister-in-law he actually needed care needs because he has Parkinson's disease. He has prostate cancer. He has other needs that could not be met within a caring environment within a home even with supports in place. But I can be assured that the facility that he is in actually has suitably qualified staff to provide his care.

MS MACRI: There seems to be this inconsistency around that training and education of the third tier workforce that appears to be a continuing issue and that includes around the ability to communicate and all of those sorts of things. Can I ask just ask you as well, in some states and territories - now, I know there is a difference between low care and high care but is there a requirement within the ACT, either within - I know in New South Wales, for instance, there is a requirement under the award for a deputy director of nursing for 40 beds or more and there is a requirement for a director of nursing under state legislation and a registered nurse. What sort of legislative base is there in the ACT in relation to staffing for high-care facilities?

MS ROSBOROUGH (ANF):   I don't actually know offhand but I don't know that we have such legislation as the other states do to that degree.

MS MACRI: Do you have anything built into your enterprise agreements or awards or anything like that?

MS MIRAGAYA (ANF):   Not specifically and we don't have enterprise agreements with all facilities. We have a number of facilities that rely on award provisions and so whatever is there. We have a difficulty within the ACT translating the modern award to those facilities as well. But where we have collective agreements, we then have a pay scale and classification structure that actually meets a nursing career structure, inclusive the assistants in nursing that we represent.

MS WILLIS (ANF):   A lot of times it's interpretation with the providers and that's how they avoid hiring registered nurses or even enrolled nurses.

MR FITZGERALD: Yet the - I think I know your answer but I'll ask it anyway - the accreditation system does in effect attempt to make sure that there is reasonable staffing. It's not prescriptive, there's no ratios and what have you. Why do you think that scheme has not been able to achieve the retention of adequate staffing if you believe that adequate staffing is in fact missing?

MS MIRAGAYA (ANF):   It may come back to pay rates.

MS WILLIS (ANF):   Pay and conditions.

MS MIRAGAYA (ANF):   I mean, even the Aged Care Standards and Accreditation Agency the standard is August 2008, on page 3 said, "The reduction in the number of nurses and the subsequent changes to skill mix is leading to a lower level of safety and quality of care and putting these vulnerable residents at risk."

They have recognised that they have problems with skill mix to provide care. But if we don't actually address the pay and conditions issue, attracting staff to residential aged care is always going to be a problem.

MS MACRI: Do you find your proximity to New South Wales, for instance, Queanbeyan, are there staffing difficulties in terms of nurses working across the border, say, for New South Wales to ACT in terms of pay rates? Is it more attractive to work in Queanbeyan than it is in Canberra or are there problems around those sort of proximity - - -

MS MIRAGAYA (ANF): We certainly find that in the acute care sector.

MS WILLIS (ANF): But not in aged care.

MS MIRAGAYA (ANF): But in aged care quite often what we find from our members anecdotally is that they're not actually given full-time employment within one facility. So they may in fact have to work over two or three facilities in a part-time capacity to actually get a full-time job which causes us some difficulty when we have outbreaks of gastroenteritis which happened a couple of years ago, we had quite a significant outbreak of gastro. But, of course, when somebody is precluded from working because they are working in a facility with gastroenteritis, they can't actually work on their second job. So that causes us some difficulty but again it comes back to how they're employed and the rate of pay that they are able to secure and why they then actually look for additional work.

MS WILLIS (ANF): My experience with aged care facilities is they don't employ full-time staff. I don't know why, but they don't. It's always permanent part-time or casual and then they can't retain their staff so they've got to go to agency staff and that's very expensive for them so they've blown their budget so they've got to make further cuts. It's the resident that suffers yet again.

MR FITZGERALD: We see great variability in that. We see that some facilities employ almost no agency staff and others employ huge quantities of agency staff. Now, in a sense, from the commission's point of view, that's a way in which you manage but we can't quite work out why that is. Is it just management philosophies or management abilities that leads to this? But it's quite stark in the way in which different services engage their staff.

MS WILLIS (ANF): Management ability.

MS ROSBOROUGH (ANF): Staffing is one of the highest costs so I think if they have part-time or casual they can actually look at their budgets and manage their budgets better by manipulating their staffing ratios. So it is probably a philosophy of the organisation to help contain costs.

MS MIRAGAYA (ANF): Which you would know from the ANF federal submission. They are looking at some formula for a patient-resident ratio. We have it in child care. We don't have it in aged care. We do have facilities where there may be 60 residents with one registered nurse on at night or in fact an enrolled nurse on at night or maybe a certificate III AIN on at night. So we would certainly support some formula for a resident staffing ratio. We're not looking to have everybody registered nurses. We accept that there is a range of skills that need to be provided within aged care and certainly we are very grateful that we have dedicated assistants in nursing providing the majority of that care. But we do need to have some formula that says, "This is safe care." The way the accreditation standard is now, it is left up to self-regulation of the provider to determine the number and skill mix of the staff to provide that care. I don't know, it might be good to let you know what it's like to be a resident in aged care.

MS CLARK: You can have an aged care facility designed with beautiful gardens and cafes and a theatre and everything else but it's no good if it doesn't have good staff. They need qualified and trained staff, staff who are fluent in the English language so that they can follow instructions or written. Most people coming to our facility now have some degree of dementia and some have other debilitating diseases which mean that the carers have to operate mechanical equipment to get them in and out of bed, to get them into a wheelchair, whatever. They need a lot of care.

There are not many in our facility that myself who can do things for themselves and speak for themselves if they're there. Now, talking now about a low-care section of the hostel, it no longer is low care, but the management get over this by saying, "Well, we have ageing in place." To get people who can look after these people, as well as people like myself, you've got to be able to keep them. They must be paid more money, otherwise they don't stay. I'm particularly referring to nurses and carers. These people are our family. When they leave, if it's someone we've been trusting for some time and have got to know, it's like losing a family member. When you lose one after another, it's very depressing.

Carers have heavy and responsible jobs and need to be paid accordingly. Residents who constantly lose their friends through death or dementia do not need to lose staff they have come to trust through less than good pay and conditions. There are 80 facilities in Canberra which cannot afford to have food cooked on the premises. They get it from large kitchens at Wollongong where it arrives chilled in trucks three times a week. It comes from [name of organisation removed] I call it Into a Reluctant Throat. We don't need large amounts of food but it should be nutritious and have flavour. We need it for our brains, most important, as well as maintaining general health as we age. I am 89 years old next month. Please don't leave it until I am dead to fix up all the things that have been said this morning.

MR FITZGERALD: Thanks very much, Mrs Clark. Can I ask you, Mrs Clark, if you wanted to make a complaint in your facility, how easy would that be to do? How easy would it be to make a formal complaint?

MS CLARK: Well, for me it's not hard, but for most of the residents, it is hard. They will not make a complaint because they're afraid of being thrown out and they will be regarded in disfavour, if you like, by the staff. They will not complain. The boss came round last night, the general manager, at teatime. The soup, I couldn't eat it. It was supposed to be minestrone soup. It was thick, it was salty and it was unpleasant. It was also very greasy because it wasn't hot. Now, I was approached by the manager - somebody must have complained - and he said to us at our table, "How was the soup?" so I said, "Well, I didn't eat mine, it was greasy." The others - he said to each one, "How did you find it?" They said, "All right." So he said, "Oh, thank you, thank you, thank you," and went away. What can you do?

Anyway, I make complaints, but the thing is, nothing gets changed. I've been chairman of the residents' committee and I resigned the other day because whatever you put forward, they say they're going to address this, they're going to address that. Nothing changes. It's very, very frustrating, so I'm going to be on the committee but I'm not going to chair it. As for making a complaint, we're only supposed to do them through a thing called an improvement log. You write on the improvement log whatever has happened and then you put your name on - or you needn't if you don't wish to, but they state that if you don't put your name on, you don't get any feedback. Nine times out of 10 in the past, you haven't had any feedback anyway. Nobody has come and said, "You're supposed to do this." One of the reasons is that the person who was supposed to come back has been on stress leave since last September and we don't know what's happening. Somebody else is trying to do her work.

You put the complaints in. If it's something about the kitchen, the person in charge of the kitchen comes very belligerently and says, "You've put this and that and you've put this and that. We do this and that." You don't get anywhere.

MS MACRI: Can I ask you, Mrs Clark, in terms of accreditation, and I presume the facility has been through accreditation.

MS CLARK: Yes, it was.

MS MACRI: Were you able to sit down with the auditors and have a chat to them quite independently?

MS CLARK: No, I wasn't. I don't know why. I think we were able to put our names forward if we wanted to see anybody but I didn't because I knew that if they got any negative feedback, then they would know it came from me, because nobody else would speak out. So I backed out of that unfortunately. I don't intend to do that again.

MS MACRI: That's a bit sad, isn't it?

MS CLARK: Yes, it is.

MR FITZGERALD: Thanks for that.

MS CLARK: Does that answer your question?

MR FITZGERALD: Yes, it does, very much so. Thank you very much.

MS CLARK: We were told at the annual general meeting we had to put complaints in through these improvement logs and not through people such as me, which is fair enough, I suppose.

MR FITZGERALD: Can I just ask you, Jenny: we've heard from your national body that you're working up potentially a national framework agreement with the industry sector, with providers. I'm just wondering to what extent that is localised to the ACT. In other words, that national framework agreement - I think that's what we're calling it - to what extent will that be involving you working with providers at this level, or is this an agreement that will be dealt with only by your national office with the national peak bodies, and how do you see that impacting if an agreement is able to be reached.

MS MIRAGAYA (ANF): I know that the draft framework was attached to the supplementary submission that the federal office made. What generally happens in the ACT, particularly because we're close to New South Wales, is that quite often a number of the agreements that we negotiate with providers are in fact framework agreements that are reflective of those in New South Wales. So I would imagine that if there was a national framework agreement that would also then flow on to when we start doing agreements with individual providers within the ACT.

MR FITZGERALD: You're absolutely right that it has come in, but can you clarify one thing for me. Does it say in relation to staffing levels and skill mix? In other words, is this only dealing with remuneration or is it going into those sorts of other issues?

MS MIRAGAYA (ANF): I'm sorry, I really can't comment on it. I've read it, but you'd probably better to speak with the federal industrial officer about that.

MR FITZGERALD: You're very much aware that a number of the other unions that also have coverage in relation to personal care workers are not supportive of the licensing of that workforce. The workforce in the aged care area is about 170,000 people, and if you extend that into disability and other areas, because they're very similar - in fact, they're the same workforce - that's a very substantial group of people to suddenly bring within a licensing regime. I was just wondering how you respond to the other unions' equally strident view that it would be inappropriate to bring them into a licensing regime. You are all on the one page about increasing training and skills development, so there's no disagreement about that. The way to get there is in disagreement. So I was wondering whether you could comment on that.

MS MIRAGAYA (ANF):   I think there are a couple of matters that need to be addressed. One is, from our experience both within the sector and as consumers, that people generally going to residential aged care facilities do not make this as an accommodation choice. We do have some that actually go into retirement villages with an expectation to age in place and then are provided with the additional care that they need. But most people who go into residential aged care facilities go into those facilities because they actually require care. As I said, with my father - his preference is to be at home, his preference is not to be in a residential aged care facility - he requires care.

So what we're looking at as an organisation is that if we are providing care then those people who are providing the care have a duty of care to provide skilled, qualified care. As much as it may be very pleasant in-home to have mum or dad or daughter or son looking after somebody who requires care, when it come to requiring skilled care, even with packages that are available in the home, as in my father's case, with the support from DVA, it was not possible to maintain him safely in his own home, he actually required care.

The statistics are there: the Australian Institute of Health and Welfare 2008, Residential Aged Care in Australia 2007-2008: A Statistical Overview on Aged Care states that the majority of residents at 30 June 2008 were assessed as high care. That's 70 per cent. By way of contrast, 58 per cent of residents were classified as high care in 1998. In addition, 66 per cent of permanent residents who were admitted during 2007-2008 were classified as high care. These are not people who go in there for an accommodation choice, they go in there because they actually require management of complex behaviours, complex care needs, medication management. These are not people who simply need a nice kind person to be caring of them, they actually require skilled nursing care,. Therefore, they need to have qualified skilled staff providing that care.

The age profile of the resident population continues to increase. 55 per cent of residents at June 2008 were over 85 years old. Over one-quarter, 27 per cent, were aged 90 years and over. Overall, only 4 per cent of residents were less than 65 years of age. These are not people who are making accommodation choices, these are people who require skilled care, and, as an organisation that supports vulnerable people who require care, we think that there should be a licensing system that provides for skilled staff with mandatory qualifications so that the care delivered to these vulnerable people - who may not be able to speak for themselves as well as Mrs Clark can speak on her behalf, but, speaking on behalf of her residential colleagues, they require skilled care. That's why we are very, very keen on having a licensing system. The federal submission, I know, doesn't say you do it like this.

MR FITZGERALD: No.

MS MIRAGAYA (ANF):   It is a timed introduction of this qualification.

MR FITZGERALD: But when the argument is made in relation to licensing - you're right, and as you have passionately done, and others have done so too - it's generally in the context of the residential aged care facilities. Yet, as you know, the vast majority of people now and into the future will be cared for in their own home, and there personal care workers are even more significant because there's much less nursing staff in that arrangement. The issue is not about the skills, the issue is about the licensing. Do you draw any distinction at all between the need for licensing of residential care personal care workers and community based care workers, or do you treat them the same, even though the argument always seems to be about what happens in residential services.

MS MIRAGAYA (ANF):   The statistics are there for residential care services.

MR FITZGERALD: Yes.

MS MIRAGAYA (ANF):   The difficulty is though that when you're caring for people in their own home there's a certain degree of trust that needs to be placed in those persons who are entering someone else's home, they need to be able to work autonomously, they don't actually have a registered nurse oversighting their care. So in many respects it may be more important. Certainly we have police checks, so that we hope somebody is a good and proper person, but there are issues related to the delivery of care within people's homes, because it's still a duty of care to provide that care and it will be provided autonomously. But it may be that you have a less complex delivery of care. Ms Rosborough could probably better comment on that, because of her experience with ACAT and dealing with people who have care packages and what may or may not be required to deliver that care within the home.

MS ROSBOROUGH (ANF):   I think in a community based environment the risk to the person who is receiving the care and the risk for the person giving the care is greater. So you do need more controls set up so that that system operates as efficiently and as effectively as it can for both parties. Residential care is meant to be equivalent to community based care and vice-versa - the choice is for the individual - which they choose to access. So the quality and skill of the person providing the care shouldn't really be any different. The training needs might be slightly different, but the quality should still be there, and that can only be done by I think licensing and mandatory training.

MS WILLIS (ANF): They need to be held accountable too, as do the providers, and not everybody has got a choice when they go into a residential aged care facility. Circumstances a lot of the time is why they have to go in, unfortunately, and they need the best care they can get.

MR FITZGERALD: I know time is running out, but I just want to raise a question. We had the Royal College of Nursing yesterday, and we have had the College of Nursing, which is different, somewhere else, talking about nurse practitioners and, what are they, specialist nurse consultants.

MS MACRI: Yes. We recommended in our report around nurse practitioners, which we continue obviously to support. But one of the issues that we have raised (a) is there aren't a lot of them, becoming a nurse practitioner is not an easy path, academically, or registration, or anything else, and it seems to me there's a little bit of a gap between that RN and the nurse practitioner, and we would be interested in your thoughts, fleshing out a little bit more around the role of clinical nurse specialists or clinical nurse consultants, in terms of some of the complex areas of wound management, diabetes. I mean, people obviously can't afford and may not need to have a clinical nurse consultant or a CNS on their staff, but need access to one. How do you see that working, so that you're complementing that more complex care within both the community and residential aged care.

MS ROSBOROUGH (ANF): Within the context of the ACT I could see that it would work quite well. Geographically, we have got a defined area, it's easy to get around the ACT. If you had a core group of trained professionals that could provide support to these facilities or community based clients, it would actually function really well. But setting up that network and having access to that network would be quite costly, and who is going to own these people and train and them maintain them is one of the issues.

MS MACRI: I know in Victoria for instance the Royal District Nursing Service has a substantial role around that area, around sub-acute care, post-acute care, providing clinical nurse specialists to residential aged care. Nothing exists in the ACT in the same way?

MS ROSBOROUGH (ANF): We have nurse practitioners that do go into aged care facilities or see community based clients.

MS MIRAGAYA (ANF): But Victoria has a substantial number of publicly-funded residential aged care facilities that are run by the Department of health. Within the ACT we do not have any public residential aged care facilities.

So although certainly there may be some outreach services with regards to continence care or wound management or stomal therapy, and I would concede you wouldn't want to have or couldn't probably afford to have those experts in every facility. There should be the ability to actually access it.

With regards to nurse practitioners, because in the ACT we are 60 or 70 GPs short, the difficulty within residential aged care is getting a GP who will actually do home visits to the facility. So that makes life difficult. Within the ACT, having access to nurse practitioners who could in fact do assessments, commence interventions, order appropriate medications, within their scope, may in fact assist residential aged care facilities not actually having to transport acutely ill residents in the ambulance service to the acute care hospitals, it may in fact prevent that sort of cost shifting.

MR FITZGERALD: Apart from the funding of these services, is there any resistance to the establishment of nurse practitioners and specialist nurses generally? Do you have barriers to that here, or is it simply the funding of those positions that would be the issue?

MS MIRAGAYA (ANF):   The nurse practitioner in the ACT requires a master's qualification, and those courses are run at the University of Canberra, and obviously people can do them externally as well. But within the ACT, prior to national registration, to be registered as a nurse practitioner you had to be employed. So you could get the qualification, but you actually needed guaranteed employment to be registered as a nurse practitioner. In the ACT there is an increasing number of registered nurse practitioners, but I would suspect that there is quite a number who actually have the qualifications but haven't been able to register because they haven't been able to be employed.

MS MACRI: That's a pity, isn't it?

MS MIRAGAYA (ANF):   It is.

MR FITZGERALD: We are over time. So are there any other final questions from Sue?

MS MACRI: No.

MR FITZGERALD: Or final comments from any of you?

MS CLARK: Yes. It's very hard for people like me in an aged care facility now, because we are counted by the other residents as kind of an assistant carer, because there are no staff about. It's people like myself the residents come to when they need help. Thank you.

MR FITZGERALD: Thank you. Any other points? Okay, thank you very much for that. We will now break for morning tea and resume in 10 minutes.

MR FITZGERALD: Thanks. If you could individually give your name and the organisation and the position you hold within the organisation that you represent.

MS CHAMBERS (AA): Kasy Chambers, executive director, Anglicare Australia.

MR MANDERSON (AA): Roland Manderson, deputy director, Anglicare Australia.

MR FITZGERALD: Thank you very much. Thank you very much for the submission. I think we've just got one on our table now.

MR MANDERSON (AA): Just that moment. That's right.

MR FITZGERALD: So I look forward to reading the supplementary submission. If you could just give your opening comments and points and then we might have a brief discussion.

MS CHAMBERS (AA): I'd like to begin as we've begun every public statement and conversation on this by congratulating the commission on the draft report. We think it does truly recognise the level of reform that's needed in the sector and certainly feel that it's going to help create a system that is going to work for most Australians. So we'll now hone in on the Australians we think that it perhaps won't work for and the people that we are here to try and represent. They're probably the most marginalised and vulnerable older Australians. They're people with special needs.

We do comment that perhaps the draft report doesn't perhaps explore the term "special needs" as much as we would perhaps want it to. We're talking about people who are homeless, people with mental illness, people who have had long-term life experience of disadvantage which has led to them often becoming prematurely aged due to harsh lifetime conditions, I guess. We're also becoming concerned about people who age in rental accommodation for various reasons.

We want to look for the same objectives for these Australians as all others in their ageing for dignity, autonomy and quality. We're just concerned that the general approach of the draft report might not get that for this group of people, that perhaps the market might not necessarily want to form services that will work for these people. We're not here to advocate for the not-for-profit sector. We're here to advocate for those who are in deep disadvantage. But for those most vulnerable and marginalised, it's hard not to think the not-for-profit sector does seem to have a special role there and that we're just, as I say, concerned that a market based approach may not pick up on those people.

We would like to make some comments and we have in both of our submissions about an age-friendly society. We also are working, as I'm sure many other groups are, with a parallel report by the Productivity Commission into the National Disability Insurance Scheme and we were looking at the three-tier kind of model that is mentioned in that report of a tier of general support, a tier of almost preventative support and then a tier of specialist support.

We did see that that would be an appropriate model for viewing the aged submission as well, in that in tier 1, which includes all 22 million of us, we would be looking for an age-friendly society. An age-friendly would be inclusive of all. It's around housing, it's around the design of communities, all those sorts of things; something that fits someone in a wheelchair, fits someone with a pram, fits somebody with limited walking ability.

Tier 2, if we think of it like this, would pick up on those kind of health promotion strategies, so that those people who are prematurely ageing, which for a lot of our organisations is who we're concerned with. We're seeing people in their 50s who are exhibiting what the rest of the population in their 80s are showing. Nutritional programs, anti-fall programs, those kind of things. But also in there is the kind of outreach for people who are ageing - I wouldn't say "normally", but health promotion, preventative and early intervention kind of programs. Then tier 3 would be those quality residential and community care programs for people who are aged. That's where we then list our concerns about workforce development and accreditation.

We wouldn't see that ageing funding or ageing policy would necessarily concern itself with the first tier, but if we don't get tiers 1 and 2 right, then that third tier struggles more. So we've started to apply that kind of a model to our thinking. Our final comments in the opening statement are just that we, like lots of other people, like the commission has recognised, just want to acknowledge that we need to be careful through the transitional arrangements. We are very concerned about our clients. That will mean that there are difficulties for some of the providers. We're not here to advocate for providers, but for clients, but we do need to make sure that no clients become disadvantaged as we transition those arrangements through.

MR FITZGERALD: Thanks very much. If I can just go to the tiers, I think that is actually a very helpful construct. As you know, there has been an attempt to make sure that the disability and aged care interface is looked at, and we have a lot more work to do on that, but I do agree the way you've set up the discussion of a tier that deals with age-friendly communities, a second tier about social supports and preventative stuff and a third one which is really the formal aged care system, is a neat construct. It is appropriate in disability and is absolutely appropriate in aged care. So I think that's a very helpful contribution.

Can I just go to the first part, which is the vulnerable and marginalised members of society. Since the draft, we've had discussions with a number of - I must say it's nearly all not-for-profit organisations that specialise in providing support for people experiencing homelessness, people with substantial mental health problems and so on. So what we're trying to do at the moment is to say what is the best way to deal with those particular cohorts. I'd like to just explore with you what you think the most appropriate way forward is in dealing with those particular groups.

If I can start with the actual formal aged care services and then secondly it's about the housing and general community supports. So what is your state based agencies' and yourselves' thinking around the way in which we should deal with those special needs cohorts? If we can just break them down a little bit. The services that especially wish to cater from homelessness or vulnerable backgrounds, what is your general approach?

MS CHAMBERS (AA):   The specialist needs are quite specialist in terms of their diversity, so we've got a service based in Adelaide that works with people. For example, there are extra costs to caring for people. They have prematurely aged, a lot of these people. They are wishing to maintain their lifestyle, but they haven't been used to, for example, smoking inside before. So we run even programs on safe smoking, the use of ashtrays, really quite different things. We're feeling that in order to keep those kind of services and courses around safe drinking, that kind of thing, it's sometimes, for some people, the first time that they have come into contact with any kind of preventative health promotion sort of messages, because they've not been in the workforce, they've not been collecting those in a general place, at least for some time.

The funding to work around that is quite difficult to get at the moment and a number of our services cobble bits and pieces together. Another service based in Geelong is looking at allied health kind of responses and again trying to pull bits and pieces of health or aged care funding. There is a difficulty with these groups that prematurely age because they're falling out of the aged care. I know you'll understand I'm really not talking about getting younger people back into nursing homes. These are about people who are exhibiting the same needs as those other people who are ageing. They're simply ageing prematurely due to whether it's lifetime experiences or whether it's due to demographics, like disability or being indigenous. So I really want to be clear that we're not talking about younger people in nursing homes.

MR MACRI: Can I just make a comment there, because I think it's really important. One of the things that a couple of people very stridently in our Melbourne hearings around this special needs chapter - and it was a CALD group, who very strongly said to us, "We are not special needs. We are additional needs and diversity," and probably for this conversation it would be helpful to probably look at what you're talking around as special needs as opposed to some of the other - like veterans, are they special needs or is it additional needs. Have you got some thoughts around that in terms of - - -

MS CHAMBERS (AA): I think the people we're talking about are special needs; they're people with mental health issues, et cetera. We're not going to claim any great knowledge about the gay and lesbian community here today.

MS MACRI: That's another one.

MS CHAMBERS (AA): That's another that I would say are additional needs. I think the general system needs to be inclusive, it needs to recognise people, where they're coming from. That needs to pick up on their language, their culture, their sexuality. But we are talking about people who are homeless, who have mental illness, who are providing difficulty to mainstream aged care services.

MR MANDERSON (AA): Whether they've got a supported place or not, really. They're not going to be particularly attractive, some of those people, to more mainstream services, depending a little bit on how it washes down with the cost of care. That was another one we were talking about and we've been talking about for a long time; about wanting cost of care properly assessed. But we're a little unsure about at what dimension does that costing stop when you're talking about people with real special needs. Rather than going with the model of accurate cost of care, freeing up with the supply, and allowing people then to get the money for the cost of care that they provide, maybe for all these people with special needs we need to look at something which is more block funding, more co-production, that idea in your report about, "How do we do things in partnership?"

Maybe we need to look at talking with - and I don't know whether it would be with the agency, the commission, or the government, but to sit down with some of the key providers. In this report we make the case that at this stage at least there is a case for saying that the not-for-profit organisations are groups who have objectives that you can hold them to about their social purpose and maybe that's a platform on which you can have some kind of a partnership about; how do you address the care needs of people with broad special needs?

MR FITZGERALD: We're quite open to looking at the establishment of an aged care system that specifically caters for homeless people, if that is justified. We're open to that suggestion, and I must say that the more we hear, the more logic there is in saying it; that there would be block-funded services for this particular cohort. Because the nature of the services probably lend themselves to block funding anyway, but also they are a special group.

There are, however, two other areas where we've still got to think through.

One is where you have a cluster of people with particular needs. So they're not the dominant group within the aged care, whether it's community or residential, but there's a number of them. Then there's the third one where you have the occasional person that exhibits particular mental health or behavioural difficulties associated with their circumstance. It seems to us at the moment, but I'd welcome your thoughts, that you could probably have a separate stream of aged care funding and service delivery for people that are experiencing homelessness and maybe those with significant mental health issues; they're probably related in many senses. But then we've still got this issues about, what do you do where there's a small cluster of people and what do you do with the individual, and how do we make sure that the system can accommodate those people and the cost of - - -

MR MANDERSON (AA): I guess with the individuals, to cut to the easy one in a way and leave the middle one because it's slightly more complicated, you would think that a rigorous and a fair "cost of care" process, if you're talking about just individuals, you could pick up so that a more mainstream provider, which is already taking on some people with supported places, knowing that they could be funded for that extra demand and extra need, could take those individuals on and provide them with the support they needed and, if you like, everybody else who lives with them too, because they've got the care there that they need. So I think, off the top of my head, if you break it up like that, you would think that if this "cost of care" process works, it would be able to deal with individuals.

I think when you're talking about clusters, again, maybe there's a halfway point. It's not a funding a whole operation, but maybe it is a program that - and maybe rather than tenders, but it could be an EOI process for providers in the area. If you are a cluster, you are talking about an advantage of congregating socially and community wise, as well as to the care, so you would think there would be a process, if everybody sat down.

One of the things that we put at the end of this, in terms of the transition, is to say, not only would we want the transition taskforce to be independent and to have some representation from the different sectors as well as appropriate government and agency people on it, but also it should have a reference group for vulnerable people with special needs. Because I think that needs to be monitored all the way through and I think that some of these things will need to evolve as they go, rather than be resolved in the first instance. So I think probably it's about flagging and getting government commitment to a process to develop those responses, rather than this to be locked in to what those responses might be. But I think we need to flag them fairly broadly so that there's some room in there to find out what works and what doesn't.

MS CHAMBERS (AA): Certainly where we would want to see block funding; for example, again going back to our service in Adelaide. They are working with about

32 people who are coming in with premature ageing, who have lived on the streets. They have a group of six who have Korsakov's syndrome, and they have not separated them out but are providing a slightly different day program cum services to that group. That's a cluster that has emerged from that particular group.

MS MACRI: A cluster within the cluster.

MS CHAMBERS (AA): That's right, yes. I would be thinking along those lines, that if we can build something for the biggest base of this pyramid, and even then that's the tip of the pyramid of aged care, but we're concentrating there, and then we start to filter out, back to the individual. But the cost of care is very real; that's a real issue for these types of services. It is specialist. We spoke to the manager of that service - I'm talking about staff and their needs at the moment - she said that in an average shift, they had measured it, and in an average shift their staff would be insulted, spat on, low-level aggression, an average 33.0 times per shift. Their staff understand the group they're working with, but, even so, that's a different set of training and needs.

The costs that they're putting through for those groups in terms of social programs or socialisation programs, if you like, was about $750,000 a year, but they had a very stark example of one gentleman who'd come to live with them, who before coming to live with them, in the previous 15 months, had turned up at the state health authority emergency ward that the health authority estimated he'd cost just over $1 million. He was turning up for company, I think, as much as anything else, but also for burns, bumps, falls. In the three months he's been living with our facility he's been there once. So in terms of that cost, it costs more, but the cost elsewhere is much greater.

MS MACRI: So there must be a cost, too, then in terms of staffing, with that sort of abuse. The low-level or whatever, there must be additional - - -

MS CHAMBERS (AA): They do have a lower level of turnover, but I think it's because the staff recognise that they're specialist. This isn't your average aged care service, they are paying more than the aged care service down the street. But they do have a lower level of turnover, but they have a lot more extra staff supports in place; around meetings, around supervision, around those kinds of supports to staff.

MR MANDERSON (AA): Yes, they invest in the staff they have around them in their operations.

MR FITZGERALD: I must say, that is a common theme. It does seem that the staff turnover in facilities that cater for people with very high needs, as distinct from high-care, is in fact lower. It obviously indicates that people go into those services with a desire to serve and cater for that particular group of people. But you've also raised the fact that there may be some additional supports that enter. But it is quite unusual, because you'd expect the reverse to be the case and it isn't, so that's quite interesting.

MS CHAMBERS (AA): I think it would be if those supports weren't there. Where we see community clients who are very, very difficult and have perhaps quite unpleasant behaviours, who are being supported through a generalist community care program not a specialist one, we do see a higher level of turnover, of carers saying, "I do not want to go and see Mr Smith."

MR FITZGERALD: Can I just look at the gateway. You made comments here, and we've heard it from a number of providers and groups about a "no wrong door" approach. If I can just explore this a little bit further. One of the things that we will do in the final report more comprehensively than we've done in the draft is to actually recognise that there would be services that are funded to support people who are aging, including information, general assistance, but also advocacy and support in order they are able to access the gateway. In other words, there's a whole range of supports out there at the present time. In one sense, at some point everybody has to enter the gateway, so we want to make sure that we can have the supports necessary for the person to be able to move through the gateway process, no matter how simple that is, because at the end of the day, there's an entitlement.

Now, it may well be the entitlement is access into a homeless persons' aged care facility or it may be something of a different nature. But I just want to explore your concerns about the gateway because we've had exactly the same concerns raised by people before. What I don't think is an option is to say we'll have an entirely separate assessment system for this group, because one of the benefits of this group is that people can be tracked through the whole system, but we're open. So I'm just wondering whether you could explore for me your concerns and what you think we should do about the gateway. If I could just add this - and I don't want them to be confused - but if you want to access a benefit, you've got to through Centrelink.

MR MANDERSON (AA): Sure.

MR FITZGERALD: Now, whether you're homeless or you've got other additional needs, somehow you get through that system. Now, this is a very different system for a very different purpose but there's a bit of a similarity here and we actually do want people to be able to go through it but we want them to be adequately supported in that process.

MS CHAMBERS (AA): I'd just make a very general comment. Roland has got a lot more detail on this than I have, but if you go to Centrelink, you have to get through the first gate, as it were, but if you are homeless, you start to get flagged, so you start to find your way into a slightly more specialist stream because there's a number of people that your front officer can deal with and then the people that can't move through to the more and more specialist, and that would seem to me to be something that we could deal with in one gateway.

MR MANDERSON (AA): The other thing that has come up to me through this process with our network members has been what are the links then that the gateway will have with those other organisations and will that be wide enough? There's two things. One is the kind of network operation of the gateway; sure, the gateway is the final place where an entitlement is kind of allocated, so I don't think many of us are saying, "Let us allocate because we know better." I think people are recognising that that's not going to happen and that the whole model is based on an entitlement through the gateway, but it's really about if you're thinking I guess more than the gateway operating in a more distributed way, so that it is linked more widely to different organisations so that they know their way through it, so that one of the roles of the gateway is to make sure that that communication happens - - -

MR FITZGERALD: Look, I think the way we would see it - and again we have to articulate this better in the final report - is that if you're a client or associated with, say the Brotherhood of St Laurence or Wintringham or something like that or one of the other homeless persons' providers, in many senses, those providers already provide some level of care for notional care management to varying levels.

MR MANDERSON (AA): Yes.

MR FITZGERALD: We would imagine that those people would be the people that would assist the person to get through the gateway, and when we say "get through the gateway", that might be a very simple process for these particular people, and then of course they would end up in the services that are providing the necessary aged care services for that particular person. So we do see those organisations being supported in achieving that.

MR MANDERSON (AA): Yes.

MR FITZGERALD: But some people I think have got this view that you can almost bypass the gateway entirely and that doesn't quite seem to us to be the appropriate way to do this.

MR MANDERSON (AA): It would certainly put a hole in this whole model. If we were then saying, "No, people do it themselves," then we have to then think about where does the authority come from to do that, so I think that's a whole new exercise. I guess in this submission we've come around to accepting the gateway as being the one operation, if you like, that gives the entitlement, but then our concerns are things about what's its face like? How does it deal with this range of human beings who all need to be able to access it? If they don't have Wintringham or the Brotherhood of

St Laurence or someone else to support them, then does - - -

MS MACRI: So that's their coordination. Once you get to the gateway, it's what happens in terms of - - -

MR MANDERSON (AA): It's probably a bit about feeling okay about being there too in one way or another.

MS MACRI: Feeling okay about being there.

MR MANDERSON (AA): Yes.

MS CHAMBERS (AA): There are people who are ageing in boarding houses or in private rental who wouldn't have someone like the Brotherhood or Wintringham who would know their way very well through that, so I think there's a sense that - I agree, I don't think we should have a separate gateway. I think that does sort of talk against the whole model, but also it then stops the people being assessed in the same way and that's what we're saying. We're also making an argument for someone who is 58 who is showing signs of premature ageing should still come through that gateway and still go to the same places.

MR FITZGERALD: Given that client group has some mobility, although that mobility decreases with age, the gateway provides almost a lifelong tracking of that person once they enter the system which links to the e-health records and that's actually valuable, so it actually does allow some mobility but not loss of information and previous knowledge. That's helpful.

MS CHAMBERS (AA): We'd certainly like to see the gateway acknowledge that there is such a thing as premature ageing. That's certainly something that a number of our members have told us, that the ACAT teams are not - and this isn't to blame them, but they're not good - you know, their first question sometimes is, "Is this person 65 or over or aren't they?" rather than looking at some of those premature ageing things.

MS MACRI: We've heard that again with younger onset dementia, a number of issues around that.

MS CHAMBERS (AA): Yes.

MR FITZGERALD: It's correct, isn't it, that ACAT's terms of reference, if I can use that expression, or guidelines explicitly allow them to deal with people that have premature ageing.

MS CHAMBERS (AA): They do, and I think it's just an issue of training, if you're there as an aged care provider sometimes, and that's why I like that idea that you brought up, Robert, talking about Centrelink and people coming through and then perhaps being referred on, so the gateway is a general gateway, but if people are a little bit outside the box or they get referred to a more specialist person.

MR MANDERSON (AA): Just to fly the flag for one other specialist group, people with mental illness we've mentioned, people who are homeless, they're all over that of course, but people who have drug and alcohol and other drug issues, substance abuse issues over years, they're kind of - I don't know, they're not focusing highly on people sort of looking after this at the moment, and I just think it's really important to understand that that's continually one of the factors that makes for behavioural issues, which makes for people's unpreparedness to engage even sometimes with the gateway or be inconsistent in how they engage. Again, it's about the understanding of that's who you're dealing with, along with everybody else, if you are the gateway; that's I think the thing that wasn't written into the recommendations or in the report.

MR FITZGERALD: But just looking at these groups, going back to the earlier discussion we had about perhaps a specialist stream for some special needs, clearly people experiencing homelessness fit that. To some degree, people experiencing severe mental health issues fits that as well, although there is a demarcation issue about the mental health system which I don't think will ever resolve, but anyway, that's sitting there. Are there others that you think lend themselves to that special streaming? Indigenous we've looked at, and we're looking obviously at the culturally diverse groups, but are there groups that are lost in all of this or are they the primary groups which you would look at as a separate stream?

MS CHAMBERS (AA): I think they're the primary demographic groups. As I mentioned earlier, we are concerned about people who are ageing in private rental and that's an increasing concern due to the tightness of that rental market. I'll give a bit of a plug: next weekend we're doing a rental snapshot across Australia, affordability against age pension and other pension rates. We expect that to be very low. That's not about suitability, that's just being in there. We've certainly got lots of clients who tell our community care providers that they don't want to ask for a rail in the shower or for the paving to be flattened because they're frightened that their landlord will just ask them to leave. So we have concerns about - there are some people, contrary to our previous conversation about premature ageing, who don't have access to their own houses and therefore adaptability grants and that kind of thing who are coming into residential care before they need to and who are frightened of their tenure in the rental market. So it's not a demographic group as such but it is a group that we're becoming afraid for.

MR FITZGERALD: A couple of things about that: we have recommended the development of a national framework for housing for older Australians. At the end of the day, when you're in doubt, just create framework.

MR MANDERSON (AA): It's a start.

MS CHAMBERS (AA): We've fitted it into tier 2 in our framework.

MR FITZGERALD: It's like when in doubt, just ask for another review. But actually from our point of view, because it is a complex, multi-layered and multidimensional issue, it does actually require some sort of framework development to pull it together, so it actually does have some merit. But we are interested in the strategies that we could be recommending to government more specifically than that and I'm just wondering whether - a couple of things. You're not very enamoured with our approach on home modification and design.

MR MANDERSON (AA): I thought it was limp and because it has been around for a long time, the turnover is small of all new properties, it's 2 per cent each so if we don't start doing it, it might never happen. It's no disadvantage to another human being to live in a house which has been adopted so that it will work for someone in a wheelchair or who is older and needs care. So historically if we didn't have building laws the buildings for poor people would fall down all the time. It's not as if people who build buildings are necessarily doing it on the basis of, "What's the best outcome for all human beings for this building I'm building?" Some do but most of them don't.

So it's unarguable that we need to shift the quality of housing and the formulation and the scale of housing in this country for the future and if we don't make the choice authoritatively, evidence suggests it won't happen, so there's the problem. If the commission suggests, "We think strong action needs to be taken too," we're losing the voice to actually make a change in the housing.

MS MACRI: I guess the debate came around social housing as opposed to general housing market and where do you draw the line on that. That was the debate that - - -

MR MANDERSON (AA): I guess I don't see where the line is there because it seems to me that housing should be modifiable, whether it's social housing or whether it's not social housing and housing should be energy efficient and well designed which, of course, is another factor that people who don't have much money are now facing in their expensive rental houses on the edges of the cities of Australia. So again housing should be - which is up for rent or if people live in should be, it would seem - it would be better for all of us if that housing was built that was energy efficient. So I don't actually see that there is a line.

MS MACRI: There were those that debated differently in terms of where they choose to live, how they choose to build their houses and so, you know, there is a broader debate around that and I guess for us there was a little bit of caution around universal design.

MR MANDERSON (AA): It seems to me it's not going to happen unless it is, I guess that is the reason I'm making the strong point.

MR FITZGERALD: As you know, the commission's view would be that we support the voluntary adoption of universal design principles, it's the mandating of those that is the issue. The commission has a fairly simple view - maybe not necessarily the correct view - that the overall cost to the community outweighs the benefit if you apply to all housing as distinct from more selected stock. But we take your view and your view has been shared by a number of other parties as well.

MR MANDERSON (AA): I think particularly when we talk about private rental housing which only exists as part of the broader construction of housing. We can't make special laws - maybe we can but so far people haven't made special laws for housing which is privately rented as opposed to other housing.

MR FITZGERALD: Sure.

MS CHAMBERS (AA): I think we are entering a period where perhaps for the first time we're seeing large numbers of people who don't have special needs as we've defined them today who are nonetheless not passing through rental accommodation. So I think the journey in Australia typically was that you left home, you went to uni or you went wherever, you rented for five years, you got married, you moved into a house, you paid off the house, you had your kids, they moved out, you moved into aged care, you paid a bond. We see more and more people who are living in rental accommodation into their 50s and 60s and for whom it's a lifetime choice or required choice.

MR FITZGERALD: It does raise the issue - and one of the reasons why the framework that we have recommended is important - in relation to the replacement stock for the ageing ILUs, independent living units, that were previously funded by governments and are no longer funded and what we do about that. Just your view about that particular issue. So that people can move into independent, age-friendly accommodation which is not residential aged care. Have you got particular views about a strategy for that?

MR MANDERSON (AA): We have some feedback from a range of our members saying, "We had them or we have them but we can't afford to - there is no funding in terms of keeping them at a standard that they need to be."

MR FITZGERALD: Correct.

MR MANDERSON (AA): Also there is probably other people around the community in the end. If the housing is adequate and universally designed and it works well, then it's not wasted. I don't know where the money comes from to support them. Clearly that's the problem, it's the maintenance of them or investment in them. I guess our view is they could have a useful role, particularly if you're talking now about - I can think of many people who, after a lifetime in the private rental market with no security, somewhere there - if they had some real security of tenure, and I guess that's the other thing about the private rental market - but if they had real security of tenure, then I think they would be an option for many people and there would be providers who could manage that well who are also some of the - and, again, just because I know the not-for-profit sector but also who have broader social roles in terms of housing and community services who could manage that component really well.

MS MACRI: We have even looked at this in terms of the rental market within the retirement village which doesn't exist in Australia at the moment. I mean, there was an attempt in Queensland and my understanding is that it was unsuccessful for whatever reason. But, I mean, again that is an interesting one around - it has been suggested that retirement villages have a proportion of accommodation which is on the rental. Some of the church and charitables do do that in fact.

MR MANDERSON (AA): Community housing is another part of that whole package of stuff that more of those charitables do do.

MS CHAMBERS (AA): We did some work with people living in retirement villages - not our own, I must specify - and we've brought the report with us but it was looking at social inclusion of people in retirement villages and it came up with some very odd problems, things you wouldn't have thought of where private operators had not left the room for a turning for a bus because they could fit an extra accommodation unit in. So this particular retirement village, though it was within sight of a major shopping centre, that was across a six-lane highway with a concrete barrier in the middle. A taxi didn't want to come and take people that far and they couldn't get a bus to do it because there was no turning circle for this bus or pull-in. So these people were actually - although they were within sight of a major - and I'm not saying a shopping centre is the be all and end all - - -

MR MANDERSON (AA): Well, it is for - - -

MS CHAMBERS (AA): But here was the glitterazzi of services that these people were unable to access. You can't really blame the private provider for trying to maximise the amount of income off that land mass. I know this isn't the purpose or the focus here but we did find in that report that we really need to be thinking about retirement villages and some more tighter comments around those. But I do want to stress those weren't Anglicare members.

MR MANDERSON (AA): I'm sure you've got that page, the little covering letter that we sent last week pretty well covers most of the points in the big picture area.

MR FITZGERALD: No, that's fine.

MR MANDERSON (AA): There is the issue of accreditation and assessment and quality assurance all those kinds of things.

MS MACRI: That's a good point in terms of - because again we're hearing, certainly from your organisation in South Australia who we visited, Wintringham, Brother of St Laurence (a) that the ACFI doesn't appropriately assess and fund and we've heard from specific ATSI communities again that's a problem plus accreditation. Where does accreditation fit in with these services and the appropriateness of it? I would be interested in your comments around some of that.

MS CHAMBERS (AA): Our general comments around accreditation are that we need to find a way to assess quality and, as with any quality accreditation, it can bring itself to its lowest common denominator which is a tick box. One of our services in Tasmania developed a world's best practice way of holistically working with their residents. People were writing to them from the US, from Europe to find out how they were doing it, all these kind of things. They got banged over the wrist by the accreditation agency because they weren't describing, Mr Smith's ingrown toenail as "the toenail", they were talking about "Mr Smith's difficulty in walking due to these kind of things." It does seem to us that there isn't quite the flexibility to look at how quality might be driven.

The other issue there is around innovation. We certainly feel that in order to work with these groups we do need to have some freedom for innovation and for movement. That, of course, is going to offer benefits to all people in aged care. I mean, we don't know what we don't know about how to provide services the best way.

MR FITZGERALD: Okay. Another one of the areas that you're not very enamoured with our recommendation and that is in relation to trading of supported places for, obviously, low income and low wealth residents. So do you just want to talk to us about your concerns about the tradeability of - - -

MR MANDERSON (AA): Well, yes. Some of the conversation today leads one to believe that if you had the oversights and if you had some kind of a structure or a process in place so that you were none of those things - I think the throwaway line is probably the key one there, which was we wouldn't be supportive of it unless we could see that it would improve quality and/or choice for those people who have those positions. So our fear is that if an area is a large area, if people are trading, some people who were entitled to a supported position will have diminishing - less choice as time goes by as people trade into what they are comfortable with.

MR FITZGERALD: If we were able to get the regions correct so that the equity issue about not having to move from local communities was dealt with, it still leaves the underlying philosophy, and this is what we've still got to work through, as to whether or not you believe that a system could have providers that have no supported residents and providers that have all supported residents through that trading mechanism. One of the reasons why we looked at the tradeability is exactly that; to say, well, the providers within certain boundaries can elect. If they want to have more supported residents, they can get them, and if they want to have less, they can trade them if they can find someone to take them. Some people have criticised it on the basis that a social mix model where everybody has at least some supported residents should be preserved. So I'm just wondering whether or not you have a philosophical view on what is often called "social mix" housing in this space?

MR MANDERSON (AA): Spiritus in Queensland are doing some interesting stuff with having a mix in their aged care residences-cum-villages and working with those people so that those who have got the more resources and have the car and whatever actually build some friendships and work with and help people around.

MR FITZGERALD: That's the retirement village.

MR MANDERSON (AA): Yes.

MR FITZGERALD: What about their residential aged care facilities?

MR MANDERSON (AA): Well, I mean, philosophically I think that some degree of a mix I think is important. My view is, or our view has been that we are seeing some of the evidence of kind of a choice away from mix in lots of things that are happening socially, so I guess to move away completely would be something we would find very hard, however we also recognise that there are some real advantages for some communities to be able to, and communities that need to be able to, and therefore some service providers to be able to specialise in providing them with the kind of care they will get that they need and they will never get in a mixed environment.

MS CHAMBERS (AA): I mean, the concerns that I hold are around the cost, so that if we do end up with one provider providing 100 per cent supported places and one provider able to access people who are bringing big bonds, big assets, big natural supports, we come to a very different situation. Even down to the aged care residential units fete the services that we have that have - well, for example, you will gain more money off the cake stall in a service that has lots of family members, lots of engagement than you do for Wintringham, Hamill or the Brotherhood of St Laurence. The other issue is around how we actually think of those regions on tradeability. So even if we're thinking of suburb by suburb we might need to think about bus route by bus route or something about how people are being connected to their community.

MR FITZGERALD: The problem is, under the current system and under our system, there's no guarantee as to where facilities are actually put.

MR MANDERSON (AA): No. There can't be, probably.

MR FITZGERALD: Even the licensing arrangements, which in a sense you would think have led to that, hasn't. So there is an issue about trying to over-engineer this and therefore, as a consequence of that, some people do have to move to more distant locations, but we are conscious that the regions do matter if you do have tradeability, whereas they don't matter so much if you haven't, except for the setting of the quota obviously. Well, look, I think we've over time. So thank you very much for your contribution. Are there any final comments?

MS CHAMBERS (AA): Just simply to add that whilst we are critical of a couple of areas here we haven't written in everywhere where we're supportive of. We did find that the report was overall a real step forward and a real chance for reform, and we're really excited about that. So our concern is simply for those special interest groups, that they have the same quality, autonomy and dignity.

MR FITZGERALD: We appreciate that. Thank you very much for those insights, that's terrific. All right. You've got an early mark, so we'll break until 1.15 when we resume with National Stroke Foundation.

(Luncheon adjournment)

MR FITZGERALD: Good afternoon, everybody. How are we? If we can now resume with the National Stroke Foundation. If you could give your name and the organisation and the position that you hold within that organisation.

MS NAYLOR (NSF): Certainly. So my name is Rebecca Naylor. I'm the divisional director for stroke support at the National Stroke Foundation.

MR FITZGERALD: Thank you very much for your paper, your comments. If you could just run through the key points and then we'll have a bit of a chat.

MS NAYLOR (NSF): Sure. I have just a couple of page statement prepared, so that's probably the simplest way to approach it, if that's okay.

MR FITZGERALD: Yes.

MS NAYLOR (NSF): So as the peak non-government organisation for stroke, the NSF commends the commissioners and the Productivity Commission on the general direction outlined in the draft report, particularly in terms of reducing the complexity of the current aged care system for consumers and their families and service providers. We support any moves that better integrate and link services and agencies within the aged care sector. Stroke survivors and their carers consistently tell us that the aged care system is difficult to navigate. They frequently describe their experience as falling into a black hole, unable to access services essential for their wellbeing and continued recovery.

So if I could just briefly outline the magnitude with which stroke affects the community. Currently there are an estimated 350,000 people living with stroke in Australia. 72 per cent of stroke survivors are aged over the age of 60. Between 20 and 30 percent of stroke survivors go on to develop vascular dementia, suggesting that the increase in stroke over the next decade will add between 100 and 150 thousand new cases of vascular dementia to the Australian community. Nearly 90 per cent of stroke survivors live at home and more than 282,000 live with a permanent disability. This means that stoke does and will continue to place a heavy load on the system, both health, aged care and the community sector.

So the issues that we've outlined in our submission that I'd like to highlight today, there are just 3. Firstly in relation to the aged care gateway, the NSF supports the creation of a single gateway, as this will go a long way towards simplifying a very complex system. We believe that there is a need for a mechanism to be put in place so that existing agencies work together with respect to the implementation of the gateway. For example, we'd like to understand better how Medicare Locals and the aged care one-stop shops would link in with the aged care gateway.

We know that stroke survivors and carers do not currently understand where to go for information, even when there is a central agency, for example Carelink centres. We would suggest that we have comprehensive community education during the implementation of the gateway to address this issue. Stroke survivors, as a consequence of their impairments, require information to be presented in a manner that takes account of their disability. This applies to both the range of services available, for example phone, Internet and written material, and the design of written material that's made available. The importance of this can't be underestimated.

50 per cent of carers of stroke survivors have ongoing feelings of depression. In this regard, we suggest that the baseline assessment should routinely screen for carer depression and respond with referral to appropriate forms of support, including counselling and peer support programs. The National Stroke Foundation would be pleased to be part of the planning of the gateway more broadly to contribute our stroke-specific expertise so that it's available for the staff of the gateway and older people who contact them.

Secondly, we also agree with the draft report's recommendation that community based non aged care funded services, aged care and health services need to be better linked. Stroke survivors and carers, for example, require assessment, support and referral at different time points post-discharge from the acute and rehab sectors. The experience of survivors and carers is that they are discharged from the health system into an uncoordinated, complex system of community and aged care programs. They frequently don't know what services are available or where to go to access those that they know about.

The NSF has developed a comprehensive model of follow-up to respond to this gap in service provision which we've called Stroke Connect. We've found that early assessment and referral to appropriate services has the potential to delay referral to aged care funded services. A service such as Stroke Connect needs to link effectively with the gateway. So in conclusion, in order to ensure coordinated delivery of the recommendations outlined in the draft report, the NSF would suggest recommendations be supported with the addition of the assignment of lead agencies or governmental coordination mechanisms to achieve policy goals and an evaluation strategy for the gateway. We'd be pleased to contribute our stroke expertise to the aged care taskforce. Thank you for the opportunity to present before you today.

MR FITZGERALD: Thanks very much for that. I might ask Sue if she wants to start off.

MR MACRI: The first comment, and picking up very quickly around the carers and depression, my understanding is that people that suffer from strokes as well also have a high degree of depression.

MS NAYLOR (NSF): Certainly. They do. That's right. So you're right to suggest that we need to consider that issue in relation to assessment also. I think the reason we've highlighted carers of stroke survivors is that it's frequently forgotten and that response to carer depression is often not picked up and rarely assessed fully. It is true that stroke survivors also suffer depression, but it tends to be picked up a little bit more frequently than carers.

MR MACRI: It seems to me when you talk about the interface with the healthcare system, that interface is not only just around the rehab period, but I would suggest it's probably all around that mental health issue as well. Is it easier to access those sort of services in a metro region, as opposed to a rural country region? We tend to get a little bit metro-centric when we look at a lot of these sorts of issues. I'd be interested again in terms of how your organisation perhaps connects with people in rural and regional remote areas.

MS NAYLOR (NSF): Yes, of course, it is much easier to access services in response to things like depression and anxiety in a metro area. That would be true for you and I as well as stroke survivors and carers, much harder in regional areas. I think the response to depression doesn't have to be just traditional, for example, referral to counselling services, but rather access to peer support programs and linking in with those with a shared experience. For example, for some people it will be what they need in response to feelings of depression, it doesn't necessarily mean that they have a diagnosis of depression that might require a medical intervention.

So, yes, the NSF has this new program called Stroke Connect where over time we'll build to a more fully integrated model where we envisage the program getting blanket referral from hospitals for stroke survivors to the NSF where we can follow up with them at various time points post-discharge in order to connect them with local providers and with the providers of, for example, peer support.

For some people that needs to be face-to-face and for others it doesn't. So we also offer online and phone peer programs. We have also found that, for example, the counselling industry will need to move on to more workforce training areas in the future, but we have begun with counselling, because even for those that do access it they often find that counsellors understanding of stroke and its effect is pretty limited. There's still confusion with heart attacks, for example, and they don't understand the effect a stroke can have. If there is no visible disability it's very easy to forget the cognitive effects of stroke. So we're currently working with the counselling industry to pilot a training program that we would envisage rolling out next year to try and address that gap.

MS MACRI: One of the issues that we have wrestled with I guess is the person, say, 65 years plus who has been a fit, healthy person, out there, in fact even still working, as some of us do, and then has a stroke. Where do they fit in, in terms of that? Do they come through the gateway, or do they say, "Even though I'm 65 years plus, it's not age-related. I have now got a disability." So how do you see the fit, healthy person having a stroke and where they fit in and how they connect with the system?

MS NAYLOR (NSF): When you think about the information that people need, for me that's kind of the beginning of understanding their stroke and then what is going to come for them afterwards. So the beginning of that platform, if you like, is the information we give them. For some people, they don't want a lot, they want enough so they can understand it, and that's enough. So the information they might be given in a written form in hospital might be enough for them.

For the people you're describing, it's unlikely that that will be enough. So we need to provide mechanisms for people in that position, to both access information about treatments, about the effects of stroke, about, if they want to connect with others, how they would do that, with people who have a shared experience, not just an experience of stroke, but a shared experience of stroke, and that is likely to mean, "I have been working and now I have had a stroke." So there are, for example, peer support programs that focus on people who are working.

I think that there is a need for access to information, and this partly goes to the issues around a single information platform. There's such a variety of need for information, from, "Just the beginning and that's enough," to "I need lots of detail, and where do I go to find that." One place isn't going to be able to provide all of that. So it's about being able to tell people where to go to get that information. I think people who are, let's say, 65 and they have been working as, you know, a CEO and now they have had a stroke struggle to see themselves as being part of the aged care sector. But the reality is we need a simple system.

As long as that system is able to respond effectively to the needs of that individual and to link them in appropriately according to their information needs and their support needs with the right type of services, our view would be that it's okay that it be through the gateway as long as the people on the other end of the phone - or however we're going to do it, if they're in a shopfront - understand the varying needs and experiences of people who now are living with a disability.

It's not the same as having, for example, a chronic condition; a stroke is an event, from which you want to recover. So access to rehabilitation services, access to return-to-work programs and so on is important for the 65-year-old who is working or the 70-year-old who is working in the same way it's important for the 40-year-old in the disability sector who will have access to those services. Does it matter if it comes through the gateway? I'm not sure. As long as the process is simply and accessible.

MR FITZGERALD: Whether they go through the gateway or they go through the disability assessment scheme - - -

MS NAYLOR (NSF): As long as they're under 65.

MR FITZGERALD: Well, we'll have to think about that - - -

MS NAYLOR (NSF): Okay.

MR FITZGERALD: But just assume that for a moment, because we're trying to bring the two reports into a coherency, not the same system. There's a disability system and an aged care system.

MS NAYLOR (NSF): Yes, that need to connect.

MR FITZGERALD: We can't bring them together, but we can make them connect, absolutely. Where do they go? Let's assume they get an assessment, from any system at all. Where is it likely that the majority of people who have suffered stroke will need to go to get support services?

MS NAYLOR (NSF): What are the services they'll need, is that what you mean?

MR FITZGERALD: Yes, and don't say everything.

MS NAYLOR (NSF): No, they won't need everything. But you're right, it will be different.

MR FITZGERALD: I'll just put that into context. It's very clear to us that from the gateway or any other assessment system they need to be able to access services, and those services are going to be in both community based and residential if it's aged care services. But then there's a whole lot of services that need to be provided by specialists organisations, services, because there are carers, there are services because they have particular conditions or characteristics. So getting into the gateway is one issue. Where do you go after and if there are other issues? Where do they go now?

MS NAYLOR (NSF): So are you asking me what their needs would be and what services - - -

MR FITZGERALD: Yes, and where are met now? For ease of purpose, somebody over 65, where do they go now?

MS NAYLOR (NSF): It will largely depend on what their circumstances are

MR FITZGERALD: True.

MS NAYLOR: So if you have got a 65-year-old who is in full-time employment and wants to continue to be in full-time employment, then the types of services they will want to access will be different to the 80-year-old or 85-year-old who is at a different life stage, who is unlikely to be working and is in a later stage of their life. So traditionally somebody who is part of the aged care sector would access rehabilitation services, they would access support at home - so I'm not talking about a person who is working - and carer support services. So they get that through their local council, they get that through their health care sector, and some of those people, 12 per cent of those people, will be admitted directly into residential care from hospital. The vast majority though will go home. So they will have services in their home, via HACC, they will have rehabilitation services via the health system.

A person who is 65 and working in full-time employment or part-time who wants to go back to that will require a different type of assistance, to which, you're right, the aged care sector isn't really set up to respond. The disability sector, however, is much more geared toward that. So a 65-year-old who would want to return-to-work is going to need assistance with negotiating with workplace, they're going to need assistance with adaptions at work, they'll need a different type of rehabilitation, if you like. I'm not sure the rehabilitation specialists would like to hear me say that, but, you know, rehabilitation is about getting back into life, but getting back into life as an 80-year-old is different to getting back into life as a working 65-year-old. So they'll need assistance with adaptions at work, with negotiations at work, adaptions to their physical environment and their work situation.

MR FITZGERALD: So rehabilitative services which include occupational and other therapists.

MS NAYLOR (NSF): Yes.

MR FITZGERALD: If I go to one of those services, firstly, how do I get to them; and secondly, how is it funded?

MS NAYLOR (NSF): I can't answer all of that. Many people will be referred from the rehabilitation service in the health sector to a return-to-work provider. Who funds the return-to-work provider? I can't answer that question.

MR FITZGERALD: But if you think about it logically, some of them would be insurance because they - - -

MS NAYLOR (NSF): Yes, of course.

MR FITZGERALD: But some of it would also be - I don't know. Is it the disability service? Is it the aged care? Is it health?

MS NAYLOR (NSF): Yes, I don't know the answer to that.

MR FITZGERALD: We should know the answer.

MS NAYLOR (NSF): Yes, I wish I could give you an answer that question.

MR FITZGERALD: I'll just put that back into context. It may well be that we acknowledge that there are rehabilitative services that are jointly funded or receive funding from different sources and that they cater for a broad range of clients - that is, not only older Australians but also people who are younger with disabilities, and maybe a whole range of other groups - and it's that sort of specialist services that we're talking about, where do they fit into the scheme, and you can access them through health, you can access them through disability, you can access them through aged care. The question really is, can you access them, and what is it when you get there. Then the other question for us is, who funds those.

MS NAYLOR (NSF): Yes, and I think in terms of stroke it's important that we not see this as a purely age-related disease.

MR FITZGERALD: No.

MS MACRI: No, and this is why we're sort of talking about that. I mean, the age-related, you know, the 70, 75, 80 year plus is possibly easier to deal with, in terms of the system, but, say, the 65 to 70 - - -

MS NAYLOR (NSF): The people on that cusp. But then you've got the people who have had a stroke when they were 40 who are now then going to progress through the system and enter at some point the aged care system, depending on, of course, how decisions are made about how those two things link up. The same issue then will arise if we don't have a way of connecting those two systems that is less clunky than it is currently. You will have the same problem for people transferring from one system to another, let alone those that are beginning, if you like, in the traditional aged care end. There are not a small number and increasingly there will be a larger number of stroke survivors who intend to remain in the workforce into their 70s.

MR FITZGERALD: Let's just take the current system again. If I'm 55 and I have a stroke and I have a significant impairment arising from that stroke, where am I likely to access services? Would I see myself as trying to access the array - and often dysfunctional array - of disability services - - -

MS NAYLOR (NSF): Yes.

MR FITZGERALD: - - - or would I see myself predominantly wanting to get that service through the health system. I know there is no perfect answer to this but does a 55-year-old see themselves as a person with a disability and as part of the disability system or do they see themselves as a health problem?

MS NAYLOR (NSF): Person with health issue.

MR FITZGERALD: And basically saying, "The health system should look after me"?

MS NAYLOR (NSF): No, I think they see themselves as having a long-term disability because that is what they have and it is what the health system will tell them they have also. That doesn't mean that they aren't - the message also is, "This is a long journey and you are able to make gains." All of that messaging is there. But for those that have a more profound impact of stroke, as opposed to those that may have very little impact - of which we can't underestimate that number - they see themselves as living with a disability. How they see their future then is largely dependent on personal circumstances, much as it is about the messages they get within health.

MS MACRI: So the person that has the profound impact and doesn't have a carer, where do they land up in the system?

MS NAYLOR (NSF): Depending on how high level their needs are, if you're 55 you're going to struggle because what you would need for entry into a residential care facility becomes quite difficult for that group. If you have a profound disability and you're over the age of 65 and you have a profound effects of stroke, you're going to either go home and get support via things like EACH and CAPS packages at home, via the aged care system or you will go into a residential care facility. Large numbers go home with support for periods of time. As I said, about 12 per cent go to resi care.

MR FITZGERALD: One of the things that it seems to me is that they don't end up in disability residential services, they end up in aged care residential. Is that right?

MS NAYLOR (NSF): Yes, that's correct.

MR FITZGERALD: Because I must say in my experience of disability, which is very extensive, I don't think I have struck anyone who has ended up in a disability service as a consequence of a stroke.

MS MACRI: That's right.

MS NAYLOR (NSF): But that is partly because the majority of people who have a stroke are over the age of 65. Three-quarters of the people who have a stroke are over the age of 65.

MR FITZGERALD: Yes, but that still leaves a fairly substantial percentage that isn't.

MS NAYLOR (NSF): Yes, it does.

MS MACRI: The 12 per cent that go to residential aged care, do you have any idea of the average of that group?

MS NAYLOR (NSF): No, I can't certainly find that out. That started that we collect via audits we do of acute and rehabilitation facilities nationally. I can certainly look at whether we've got that breakdown.

MS MACRI: I just ask that because of the controversy around younger people - - -

MS NAYLOR (NSF): In nursing homes, yes.

MS MACRI: - - - in nursing homes and I guess I'm trying to make that link for this particular cohort.

MR FITZGERALD: They must form part of that five or six thousand, mustn't they?

MS NAYLOR (NSF): We run a health information advice line and we certainly get calls from partners and sisters - I took one the other day, a 40-year-old who had a stroke, had a profound disability and she was struggling to find somewhere for him to go. She felt that he would be unable to be cared for at home. So certainly they are there and they would be within, you are right, that group of people for whom this is a significant issue.

MR FITZGERALD: In terms of the current ACAT system - if you know the answer to this and you made the comment which alludes to it - that if you're 55 or around that age you're going to struggle to find a place.

MS NAYLOR (NSF): Where do you belong?

MR FITZGERALD: If I were to go to an ACAT team, ACATs are able to in fact not only deal with people over the age of 65 but also people that have age-related issues and what's your experience, if any, in relation to the ability of slightly younger people being able to access the ACAT system?

MS NAYLOR (NSF): I don't have an answer to that. Rather than guessing, I - - -

MR FITZGERALD: No, that's fine. We know because of the rationing that takes place that if you're not clearly in the system, even though you're there, you have to negotiate your way in. So I was wondering how difficult that might be in this case.

MS NAYLOR (NSF): I think some of the difficulty for - certainly it will be mostly carers negotiating their way through that as well as the health professionals that might still be involved. It is complex enough the way it is currently when you clearly meet a criteria. When you sit in this far less clear bundle, then your ability to negotiate that without help is exceptionally difficult. I can't make a general statement about it but my view would be that based on the experience that consumers have that talk to us about negotiating the system currently, when they clearly fit the criteria it is difficult. When you don't, obviously it's much more difficult.

MR FITZGERALD: Just in the health system itself, we hear that the health system now deals with certain disease and chronic diseases is better. In terms of cancer, for example, there is a real strategy around how we deal with cancer. In terms of cardiovascular there is a real system that operates fairly well around that. Is that true of stroke?

MS NAYLOR (NSF): I think we've got a long way to go before we could say that's true of stroke. I think that we've certainly made gains. So with the establishment of stroke units, we have stroke plans in the states, you know, government stroke strategies and certainly there is a desire to improve the system. But, you know, 50 per cent of stroke survivors still go home without a discharge plan. So I think that just based on - that is pretty fundamental to someone's ability to then move on and make the transition from one system to another. I think we've got a way to go. A decent number of stroke units are still required to even provide the standard, good quality, inpatient care that is needed. So there is a will, there is a desire to make it better but I certainly would be confident in saying we're not there yet.

MS MACRI: In terms of the people that do go home and there is a continuing extensive rehab around OT, physio, speech pathology, the whole - where does the cost of that ongoing rehabilitation get picked up?

MS NAYLOR (NSF): It depends on the state. So in some states they community rehabilitation services that consumers can access, for example. So they can be at home and come in and get care. In other states systems like that don't exist, so you need to access it in the community. In every state there is a mixture of health system delivered rehabilitation, either in a facility or at home that is funded by the health sector. Then you would have ongoing rehabilitation that somebody would want to access. So physiotherapy, for example, that would be funded by private health insurance or privately, that you would have to pay for it yourself. It's expensive and difficult to access.

MS MACRI: This is one disease that has a myriad of different entry points into different systems, different to a lot of others.

MS NAYLOR (NSF): Not simple.

MS MACRI: It's not simple because there is a rehab side, there is a health side, there is a disability.

MS NAYLOR (NSF): I think that in relation to rehab it's the access to ongoing rehab services. I think that people would say that access to rehab facilities, different people have different experiences of that. But it exists and we've got a good solid system. No doubt it could be improved. There is a real lack of rehabilitation when you're back in the community and when you're relationship with the provider that cared for you when you had your stroke is at an end, so you finished rehab with X hospital, your ability then to access ongoing rehabilitation is dependent on means which I think is pretty unacceptable actually.

MS MACRI: It must become even tenfold more difficult if you're out in rural and regional areas.

MS NAYLOR (NSF): Right, yes. It's a major problem for people over the age of 65 but imagine what it must be like when you're 20.

MR FITZGERALD: So this StrokeConnect which you have as a follow-up service, it's a national scheme delivered through your state - - -

MS NAYLOR (NSF): The National Stroke Foundation doesn't have a federated assistance and we're a national body. We're at the beginning stages of delivering StrokeConnect and we're looking to deliver a more integrated program as we're able to access the funds to do that.

MR FITZGERALD: Who funds you?

MS NAYLOR (NSF): We do at the moment?

MR FITZGERALD: Yourselves.

MS NAYLOR (NSF): We're currently negotiating with state government in various states to access some government funds to deliver the integrated model.

MR FITZGERALD: Through the health budget?

MS NAYLOR (NSF): Through health, yes.

MR FITZGERALD: Just in relation to your comment about the Medicare Locals and the local hospital networks that have been merged, we absolutely agree that we need to make sure that the aged care system is better aligned and better connected to health care but it is actually difficult to know in the absence of those being finalised whether or not we should be modelling the aged care system, particularly in terms of its regional nature which we want, on either one of those or neither of those.

MS NAYLOR (NSF): That is understandable. I think the point we're trying to make is let's not forget these things are being developed and as they do we need to find a way to connect if up or we won't be much better off then we are now. There is a real risk that if we don't pay careful attention to linking up all of those bits that the consumer experience of negotiating their way through won't be very much different to what it is now. It would be such a missed opportunity.

MR FITZGERALD: We agree but it's a bit tricky. It's also a bit tricky because it's not clear to me that the local hospital networks will actually link in with the Medicare Locals.

MS NAYLOR (NSF): No, it is not really clear what Medicare Locals will exactly do, is it, yet?

MR FITZGERALD: No, not yet.

MS MACRI: It's a nice name.

MR FITZGERALD: We're hopeful.

MS MACRI: Or is it?

MR FITZGERALD: We don't know. Some don't think so. We're out of time but that has been a very valuable presentation.

MS NAYLOR (NSF): We're happy to provide any further information at any point if you find it useful.

MR FITZGERALD: I'll ask this question - and I should know it - the commission's report on disability, you have obviously looked at that report and I presume you're going to make some comments on it.

MS NAYLOR (NSF): We will, yes.

MR FITZGERALD: Are the people that are affected by stroke with severe impediment - because that scheme is only about severe impediment, it's not about everybody with disability - does it adequately include this group?

MS NAYLOR (NSF): Do they currently adequately - - -

MR FITZGERALD: In our draft report - - -

MS NAYLOR (NSF): Does it encapsulate - - -

MR FITZGERALD: - - - does it encapsulate - - -

MS NAYLOR (NSF): The broad descriptions of which groups fall into this report and the suggestions, the recommendations made around that I would suggest do adequately pick them up, yes.

MR FITZGERALD: That's helpful. Okay, good. Thank you very much for that, that has been terrific. Thank you very much.

MS NAYLOR (NSF): I appreciate your time.

MR FITZGERALD: If we could now have the Palliative Care Australia body. If you could give your name and the organisation and the position you hold in that organisation for the record.

DR LUXFORD (PCA): Yvonne Luxford and I'm the CEO of Palliative Care Australia.

MR FITZGERALD: Thanks very much. I think we have received a brief submission, thanks very much. If you would like to make some opening comments, that would be great.

DR LUXFORD (PCA): Sure, and feel free to interrupt me at any time also.

MR FITZGERALD: As I always say, she will.

DR LUXFORD (PCA): Firstly, thank you for the opportunity to present today and I'd like to start by explaining Palliative Care Australia is the peak national body representing the palliative care sector and those stakeholders who share a commitment to quality care at the end of the life. PCA believes that all Australians should be able to die with their preventable pain and other symptoms well managed, with the people they wish to be present and, whenever possible, in the place of their choice. I would like to place on the public record that PCA commends the commission's draft report and recognition of the need for improved funding and availability of palliative care. The report is a real commitment to enabling older Australians to have more choice, control and flexibility in their care options and it is a great step forward in ensuring that there is continuing investment in aged care, leading to ongoing improvements in meeting palliative care and end-of-life needs for ageing Australians.

Obviously we shouldn't underestimate the links between aged care and palliative care and if you look at the latest statistics from 08-09, it provides a real reality check there of around 162,000 residents in aged care, 50,000 died. So when you look at statistics like that, what we're seeing is that almost a third of residents die in any given year. So this means that we really need to recognise palliative care as an essential element in aged care and facilities must be adequately resourced to deliver quality of end-of-life care. We would like to see the final report give more attention to supporting this through building workforce capacity, competency and resources.

PCA has contributed two submissions, both of which have been through extensive consultation with our members and I'd like to emphasise some key points in addition to the material we have already submitted. To start with a key financial point we are concerned with the recommended funding mechanisms for palliative care. Case mix payments are proposed in the draft report but we couldn't seen any evidence cited to support this approach and we're concerned that a case mix funding model is inadequate for palliative care which relies on a multidisciplinary approach with different team members providing different levels and types of care at different times. We believe that further evidence needs to be gathered to demonstrate the case mix payments will truly be adequate across both residential and community settings and I'm also aware that the college of physicians has recently prepared a statement which we collaborated on around subacute funding and we also found that case mix was appropriate for subacute funding.

MS MACRI: So what is appropriate?

DR LUXFORD (PCA): That's the multimillion dollar question, isn't it? I don't know that we've got an answer to that as yet. Some of our members have suggested perhaps a mixture of block funding and case mix funding could be the direction to take. But to be honest I don't think we've got a clear answer to that either.

MR FITZGERALD: As you're well aware, the thrust of the hospital reforms is based on moving hospitals onto the case mix funding approach in its simplistic terms which operates in Victoria most extensively and in some other jurisdictions.

DR LUXFORD (PCA): Yes.

MR FITZGERALD: So I suppose in a sense we were following through on that approach.

DR LUXFORD (PCA): Except that case mix is developed for acute. It is developed around the DRGs, it is for acute care and subacute is specifically outside the DRGs which is why it hasn't really been applied previously.

MR FITZGERALD: If we just break it up. If we take residential, you're right, one can predict with some certainty the sort of levels of death that will occur over time. I mean, not every year but I suppose there is a degree of predictability. At the moment the distortion is that so many people are transferred into hospitals at that time and, of course, everybody has said to us that there is a desire, both by providers by staff and obviously that that not happen unless it's absolutely necessary. So we've got that occurring. So if we were able to reduce the numbers of transfers from residential aged care into acute care at that end-of-life stage, that would be of great benefit and I suppose you could look at some sort of block funding.

When you come to the community area, that's a bit trickier because there the predictability is less, unless we were having palliative care teams operating exclusively in that area, in which case you could actually fund that service. Am I making myself clear? Case mix looks at the individual service provider, block funding is where you have a service provider that delivers almost exclusively or very substantially a set of defined services. So should we look at residential and community care separately or the same? You don't have to have an answer for that.

DR LUXFORD (PCA): No, I don't have an answer for whether they should be looked at differently or the same but I would suggest that there are examples where palliative care teams work specifically just in community care such as Silver Chain in WA which does receive block funding as far as I know - you could easily confirm with them what their funding mechanism was - and that seems to be a good model for service within the community.

The second main point that we'd like to make is about capacity building. An expansion in the range of aged care services offered must be complemented by an expansion in the capacity and competence of primary health providers who must ensure that end-of-life care is acknowledged as a basic core competency included in the core curricular of health and aged care worker education and as an element of ongoing professional development. Until end-of-life care is regarded as part of the normal scope of practice of all primary health care professionals, this will impact on the quality of the service being delivered. This need was also recognised by the National Health and Hospitals Reform Commission.

As you have acknowledged in your draft report, access to and quality of palliative care is diverse and inconsistent in residential aged care. Some aged care facilities enjoy ready access to GPs who are well skilled in palliative care and to specialist palliative care teams, but many facilities suffer, even from a lack of GP availability or a lack of access to GPs that have adequate levels of skill and competency in end-of-life care.

One issue that we continually hear anecdotally is the reluctance of GPs to prescribe opioids at a level that's appropriate for pain management and it would be really useful in fact to investigate whether this is really due to the lack of understanding of end-of-life care management or other concerns such as medication management within facilities.

PCA was previously funded by the Commonwealth government to provide an education program to aged care staff, supporting the guidelines for a palliative approach in residential aged care and ongoing education and support is needed to ensure that these guidelines and the soon to be released guidelines for a palliative approach for aged care in the community setting are understood and utilised around all services.

Barriers such as the lack of registered nurse availability, medication access and availability of appropriate medical support, especially GPs, could potentially be alleviated through enhanced linkage between residential aged care communities and community health and/or hospital outreach staff. As you just mentioned with the last speaker, a linkage in with the proposed Medicare Local and local hospital network arrangements could facilitate this but we certainly need more detail.

PCA has developed the standards for providing quality palliative care for all Australians which clearly articulate and promote a vision for end-of-life care and we urge the commission to formally recognise these standards as vital to the delivery of palliative care for older Australians and to consider linking these to residential aged care accreditation standards. With funding from the Commonwealth, PCA manages the national standards assessment program for palliative care services across the country which is a program of continuous quality improvement based upon the national standards. We are currently consulting closely with the aged care sector about the potential to introduce a similar program into aged care and the message that we're hearing from this process of engagement is that the sector would like to see the commission recommend the introduction of a quality improvement program to foster better delivery of end-of-life care as opposed to a mandated punitive approach. Implementing standards for palliative care into end-of-life care is actually internationally pioneering work which we need to foster and support.

As you know, another barrier to the provision of adequate palliative care is the mistaken belief in the application of the ACFI that palliative care within residential aged care facilities lasts for only a matter of days or at most, a few weeks. Consistent with the WHO definition of palliative care which is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, this is not so. It is also not just about pain and symptom relief, although they are important as well. The transition to a palliative care pathway needs to be seen as, in many cases, a gradual one involving seamless care which with good management can occur over many months and we need appropriate planning to support aged care facilities to work towards providing quality care for people with a terminal condition, including appropriate palliation, pain and symptom relief, as well as spiritual support and bereavement counselling and support, both for the dying resident, their family and loved ones, and also for other residents and staff.

PCA also recognises that access to community care must be improved. In many situations, care is fragmented across providers and settings which can lead to a lack of continuity of care. Quality care at the end of life requires a multidisciplinary approach which draws together a large range of providers to meet the patient's and family's physical, social and emotional needs. I know that Bill Silvester and the Austin Health team spoke with you a couple of weeks ago and you may be aware that PCA is collaborating with that team to develop education about advanced care planning for aged care staff. Health and aged care workers across all levels of the system should be skilled and educated to provide end-of-life discussions and advanced care planning with patients and their families and carers. PCA strongly recommends that national legislation guidelines and information are developed to encourage people to express choices about their care and PCA would welcome the opportunity to collaborate on this.

So in conclusion, our recommendations are aimed at achieving the important goal that services for older Australians must assist them not only to live well but to die well too, providing comfort that they will be able to die with their pain and other symptoms well managed. The ideal of quality end-of-life care for all is an achievable outcome for all ageing Australians and we thank the Productivity Commission for sharing this aspiration.

MR FITZGERALD: Thanks very much. I'm sure Sue has got some questions. Just one question: going back to your statement about what is palliative care - and I suppose without any experience at all - where do you move from the general care of somebody that's ageing and moving towards death and it suddenly become palliation? Now, in a sense it doesn't matter, but it does actually matter if you're going to have a different funding scheme for that.

DR LUXFORD (PCA): Sure.

MR FITZGERALD: So how do we deal with that issue in aged care?

DR LUXFORD (PCA): It's interesting, there's a program that's being run in primary care or with GPs in fact in Britain. It's called the "gold standard framework" and one of the tests within the gold standard framework is the element of surprise.: would you be surprised if this person died within the next six to 12 months? From that point, you actually recognise that that point is going to require palliative care if there is no element of surprise that they would die. I suggest that a very large proportion of people who are moving into the aged care system, especially into residential aged care, there would not be an element of surprise if that person died within the next six to 12 months.

MS MACRI: We've had this conversation around palliative care can be six months, it can be six weeks, it can be longer, and where does end-of-life and palliative care - where's the nexus between that and the blending? I mean, when you go out, there's still confusion within the aged care industry around end-of-life versus palliative care.

DR LUXFORD (PCA): I think that is partly around the current funding system where it sits with the ACFI, in that people want to delimit it to being that very last few days of life or the last couple of weeks of life, instead of providing truly needs based care and looking at what that resident needs and recognising that you can see this person is likely to die within, let's say, the next six months, whether due to frailty, complex chronic disease or another reason or a combination of reasons obviously. That doesn't mean that they need necessarily extremely complex care for that entire six months but they certainly would need adequate consultation with medical staff to ensure that their needs are being properly met and proper assessment to meet those needs.

MR FITZGERALD: When do the conditions associated with dying increase the level of cost of care associated with the dying? In other words - and I don't always want to bring things back to the dollars - but if we are talking about either a change to ACFI and/or an alternative funding mechanism for palliative care and end-of-life care, there is an issue as to when you move into that.

DR LUXFORD (PCA): Sure.

MR FITZGERALD: One of the issues is when do the costs increase, when do you incur additional costs over and above that which you would incur in the general support and care of the individual? When does that occur? Because that's really, in a sense, the trigger point for a different funding level.

DR LUXFORD (PCA): Absolutely. I think it's a really interesting question when you bring it back to the dollars like that because on the one hand you've got, as you mentioned yourself, so many residents are actually transferred into acute care which is much more expensive. If you end up in ICU or something it's extremely expensive, as opposed to palliative care which is a less expensive option. On the other hand we simply don't have the data to be able to answer your question adequately and at the moment the Department of Health and Ageing is trying to gather better data about spending patterns et cetera within palliative care but at the moment we simply don't have the data so it's quite difficult to answer that question. But at least we know it's cheaper than acute care.

MR FITZGERALD: That's indisputable. That's not in doubt.

MS MACRI: But that comes back to that sort of palliative care, end-of-life care because, as I say, palliative is not necessarily end-of-life care. Palliative care can go on for considerable lengths of time.

DR LUXFORD (PCA): It can.

MS MACRI: So I guess for us in terms of - and it comes back to the funding and the resourcing - is that intense period and I guess that's different for everybody.

DR LUXFORD (PCA): It is different for everybody and we would also prefer that it not have a time limitation as there tends to be now obviously. I mean, it really does have to be needs based care.

MR FITZGERALD: But in a sense the case mix approach is a swings and roundabouts approach. Case mix by nature provides an average cost, not the real cost. In other words, there are some patients that will require much more extensive care and there are some that require less care and at the end of the day you come up with an average cost for whatever the treatment is. I'm not necessarily suggesting you can do that with palliative care and end-of-life care but that's what you would get, that swings and roundabouts so you don't have to actually deal with the individual circumstance. But in the aged care it's actually more tricky than in the hospitals because in the hospital you actually have a very clear entry point in to that. Here we don't, we have this moving forward. Moving from that, Sue's probably got one about accreditation.

MS MACRI: Again, where you talk about it might be appropriate to formally link the palliative care standards to the aged care accreditation. We have had a lot over the last few weeks around the inadequacy at times of the accreditation standards to really reflect the quality of care and I guess for me adding another layer around, "Was good palliative care provided or not provided," in terms of how that would be measured in an accreditation system that currently exists.

DR LUXFORD (PCA):   I think that is a really interesting point also in that some of the providers we have spoken to have certainly encouraged that the standards be linked into the accreditation process as a mechanism to ensure that they are followed. But as I mentioned with our investigations as to whether to expand our quality improvement program into aged, the feedback we're getting around that is that rather than having it strongly linked into accreditation and be a prod, as it were, that instead it simply be a strong quality improvement program based around that standards. The standards already cover primary care as well as specialist palliative care teams but we would certainly like to see that recognised within the final report.

MS MACRI: Would you see that if you kept it outside that you may have better success than if it gets melded into the accreditation?

DR LUXFORD (PCA):   It certainly has great success at the moment the program that we run and it does sit outside accreditation. But what services find is that what they develop for the NSAP program, as it's called, is very useful for their accreditation in fact and surveyors who are now coming around to accredit services are actually asking to see their NSAP material as well. So they find it very helpful to do that quality improvement work and identify their priorities. I can see that aged care could certainly have the same benefits.

MS MACRI: So you're talking about the ACHS EQuIP model which is currently in the acute care sector?

DR LUXFORD (PCA):   Yes.

MS MACRI: Not your program that's in residential aged care.

DR LUXFORD (PCA): Our program is not in residential aged care at the moment. We're just scoping at the moment.

MS MACRI: Yes, and this is where you talk about here then linking that program in.

DR LUXFORD (PCA): Yes.

MS MACRI: So in the acute sector it is linked into the EQuIP program, I take it.

DR LUXFORD (PCA): No, it's not linked in. That's what I'm saying, it's a quality improvement program that just stands alone but services find that it's very useful for their accreditation process.

MR FITZGERALD: Given my ignorance, what is your quality improvement program. You're saying we should recommend that which sounds eminently sensible except what are we actually recommending?

DR LUXFORD (PCA): What the program does at the moment is it's a program where services look at the standards, they identify whether or not they are meeting the standards and what their priorities area for improvement and they build upon that with support, with peer mentoring et cetera to personally identify what they need to do better and to improve - - -

MR FITZGERALD: That's provided through organisations such as your own.

DR LUXFORD (PCA): Yes.

MR FITZGERALD: So it's your program.

DR LUXFORD (PCA): Yes.

MR FITZGERALD: In order for you to do that, are we assuming that the government funds you directly to do that - - -

DR LUXFORD (PCA): Yes.

MR FITZGERALD: - - - or do the service providers pay you to do that?

DR LUXFORD (PCA): No, it's free to the service providers.

MR FITZGERALD: You're doing that in hospitals at the moment.

DR LUXFORD (PCA): No, in palliative care services so some of the are hospital based, some of them are in the community.

MR FITZGERALD: Have you attempted at this stage to seek government support for that program or are you just still developing it?

DR LUXFORD (PCA): The government has actually supported us in scopings, its transfer into aged care. At this point in time we're still in negotiation. We have an aged care reference group that we have been meeting with regularly and it's actually really quite exciting what's coming out of that.

MS MACRI: That's through the Department of Health and Ageing - - -

DR LUXFORD (PCA): That's right.

MS MACRI: - - - and also it's a reference group through DoHA.

DR LUXFORD (PCA): They fund us to do it so PCA is completely running that at the moment. But, yes, the Department of Health and Ageing certainly pays for it.

MR FITZGERALD: In relation to the workforce capacity, there are significant issues that have arisen in relation to the training and competency of the workforce, particularly in the personal care area which we have heard a great deal about and no doubt we'll hear about that in the next few days as well. But I was wondering, in relation to this are of palliative care and end-of-life care, is this something that is better dealt with as a professional development or practice development type approach or is it best dealt with in the actual core educational training? The reason I raise that, particularly for cert III and cert IV workers there is an endless array of problems with the current system that everyone wants more in the courses.

Now, that is not unfair except to say we may be asking too much of the core program. So I was just wondering whether these sorts of very important areas are better dealt with either in that core or as a post - - -

DR LUXFORD (PCA): I think it absolutely has to be both. It has to be a core competency and not just for the cert III and IV workers but also for the nurses, for the GPs who are coming in. It has to be a core competency for all health professionals, that's really important. For cert III and IV I would think that the guidelines for a palliative approach definitely should be incorporated into that training, but as you know, there's such high staff turnover et cetera and as you also said, there's so much more you need to keep learning, there also has to be ongoing continuing professional education.

MS MACRI: In the organisation - - -

MR FITZGERALD: Just on that, in relation to registered nurses and enrolled nurses, is palliation and palliative care generally a core component of those courses?

DR LUXFORD (PCA): It largely is now. There is a program called PCC For You which is an undergraduate program that includes palliative care, but it's not to any great degree. The extent to which that level of understanding is maintained, we don't really know. We haven't really assessed that.

MR FITZGERALD: If you were to increase the level of training, given the limitations of undergraduate training and you introduced the quality improvement framework into the residential aged care providers, do you have any sense as to how that would impact on the current transfer rate to acute care? Are we looking at significant reductions or are there other things that need to change? One of the things we've heard as we've gone around visiting residential aged care facilities is even if the staff have the capacity, they lack the confidence, and there's this other factor, that many of the carers and family members almost implicitly want the person to be removed into the hospital, so if we did this, will this significantly change this exceptionally expensive and disruptive and sometimes unnecessary transfer?

DR LUXFORD (PCA): I think the short answer is yes, it will significantly reduce the number of transfers to acute care, but you also need to have in place advanced care planning and make sure that's well understood, make sure that advanced care plans are linked to any electronic records, and obviously that people actually look at the advanced care plans and agree there. Obviously you need more community education around that. We also need the GPs to understand what's going on and they can be the linchpin in some circumstances, in that the facility may call the GP and say, "What do we do?" The automatic reaction is, "Send them to hospital." So we need to ensure that GPs are well and truly educated here as well.

MR FITZGERALD: Just going to the community care one, and I know we've run out of time, you mentioned the Silver Chain model in Perth. Is that, to your experience, the best model in relation to the provision of palliative care into the community? Is that sort of the gold standard which you - - -

DR LUXFORD (PCA): I think there's a number around. It's just that Silver Chain happened to be one that jumped to mind at that point in time, but there certainly are a number around.

MS MACRI: Yes, there's a number in each of the states.

MR FITZGERALD: Thank you very much for that. As was with the last presentation, that's been very valuable. It is the area we're looking at and there are really substantial gains for everybody if we can actually improve the quality of palliation and palliative care in residential aged care facilities and community settings.

DR LUXFORD (PCA): Thank you. I did mean to also mention - sorry, just briefly - that since the draft report came out, the Commonwealth has released their national palliative care strategy which also links into residential aged care which may be worth referring to.

MR FITZGERALD: Yes. Thank you very much for that. That's terrific.

DR LUXFORD (PCA): Thank you very much.

MR FITZGERALD: Thanks very much. If you could both individually give your name, the organisation and the position you hold within the organisation you're representing.

MS SWEANEY (ACG): I'm Gayle Sweaney, Anglicare ACT Goulburn.

MR FITZGERALD: And your position?

MS SWEANEY (ACG): Aged care business manager.

MS STEIN (ACG): Irene Stein, and I'm the manager of the research and policy unit.

MR FITZGERALD: Good, thank you very much. Anglicare Australia we heard from this morning and we have met with Anglicares around the countryside, so we've very happy to have the Canberra and Goulburn perspective. So if you'd like to give your opening comments, then we'll have a discussion.

MS STEIN (ACG): Firstly we want to thank you for the opportunity of being able to come and talk to you face to face rather than just rely on the medium of the print. I think the report opened up many more questions I think than you probably have days in your life to answer, but there were some things for us that we'd just like to highlight if we can have your indulgence.

MR FITZGERALD: Please.

MS STEIN (ACG): One area of concern for us was there's a plethora of reports out there at the moment dealing with aged care and aged care related issues and into that matrix is thrown the Henry tax review. I guess one of the questions that we certainly don't have any idea about, and I don't expect that you guys will either, is how will the horizontal and vertical integration of all this information that's been collected actually occur? In terms of the quality process around that, how will that be, I guess, constructed and how will the outcomes of the melting pot be evaluated?

We've seen from the government in the last probably 18 months its reluctance to pick up holus-bolus reports of this nature and only takes stuff that's going to actually increase their fiscal capacity. Some of this is going to cost and some of it is already there. So we just wanted to put the issue of horizontal and vertical integration clearly on the table.

For us, a second issue and very close to both Gayle's and my heart is education. I'd like to talk about the aged care career pathway program of which Sue was one of the pioneers. This was a program - and it's still going to this day and I think there's probably been 250 registered nurses in New South Wales that's been through it - and it replaces the new graduate program for registered nurses wanting to go into the acute sector. We would like to recommend that some funding be set aside to actually strengthen and make more robust the inroads that that program can have.

I did some statistical analysis I think five years after we commenced that program and 70 per cent of the registered nurses were still retained in the aged care sector and of that, 35 per cent were in a secession management training program, so it certainly has worked. I think that it's a model that could be taken and adapted across. It was essentially a consortia of providers and I can remember everybody saying, "This is not going to work," because it had the profit and not-for-profit sector and it was backed very heavily by the two industrial bodies of New South Wales in the aged care sector, and together it worked. We had many, many people go through it.

MS MACRI: Can I just ask - I'd forgotten all about that to be honest - - -

MR FITZGERALD: I was going to say I hadn't heard it mentioned in all the public hearings we've done so far.

MS MACRI: But it was a fantastic model and it would be really helpful if you could send across to us a little bit more information if that's still going.

MS STEIN (ACG): Certainly. It's still going, yes.

MS MACRI: It probably was one of the best models for new grads, attracting and retaining new grads into aged care, so some info around that would be fantastic that we can have a look at, because one of the things we did raise in the report is around RNs and their management and leadership skills as well, so there's a whole gambit of issues around that.

MS STEIN (ACG): We actually did some business with one of the universities, the University of Western Sydney it was at the time, and they were giving credit for some of the units that were contained in that program, so it did have legs and it was a good model, so I'll get that to you.

MS MACRI: Yes, that would be great.

MS STEIN (ACG): I guess hand in glove with that is the research aspect. The report talks about a clearing house and I guess what we'd like to put on the table is the fact that we've got a lot of centres around Australia doing piecemeal aged care research. Sometimes it's driven by political agenda, sometimes it's driven by religious agenda, other times it's I guess driven by a particular person's passion. I just wonder how you're going to bring this disparate groups of people together into a clearing house run by a superbody that is going to actually highlight the areas of specialty, highlight areas of need for further research and doing some sort of gap analysis on what exists would be a starting point, but even that would be daunting.

MR FITZGERALD: There's several approaches that are possible. One is you leave it in fact to the research sector itself, such as ARACY, which deals with, as you know, substantial research around the issues of child and youth wellbeing. Of course that has a huge number of collaborators in that. In a sense, they, the researchers, and interested parties come up with a research agenda. The alternative is not to do that, but simply to have a clearing house for research. At the moment there are a number of clearing houses that are funded. For example, there's an indigenous clearing house that has just been established through AIHW and there are a number of clearing houses where the research and the evaluations that are out there in the public domain are literally brought together and re-disseminated, sometimes with analysis, sometimes not. The indigenous clearing house has some analysis in relation to that going on.

So in terms of the clearing house, it is really a way by which what is being done can in fact be re-disseminated. The second thing we talked about is a clearing house for data, and that's a slightly different nature where we did indicate that the regulator could be the disseminator of that. Many people have said to us they don't think that's appropriate. Notwithstanding that, the regulator will be collecting a huge amount of information which currently the department collects and does not disseminate, but under our plan they would collect it and they would disseminate it. So I think there's a couple of models for the exposure of the research.

All that aside, none of that actually deals with setting a research agenda. We haven't canvassed that. It is possible both in the disability and in the aged care area that there could be a government body or a part government body that actually does try to set a research agenda. On the other hand, it may well be that's not the issue. The issue is actually knowing what's out there and letting the researchers actually work that out. So we're open to suggestions.

MS STEIN (ACG): I don't have any suggestions, other than to raise it as a concern that there's a lot out there and just from my limited experience, trying to pull it together in any sort of meaningful agglomeration and working out what is good and what is bad research - - -

MR MACRI: That is the other one too. There's people doing research through their PhDs and there's people doing masters and having a research base to their masters and I guess it's about the publication of that research, it's about identifying what is good research and what is going to add value to where aged care goes. It really is a difficult one. When you started talking about a gap analysis, I nearly fell off the chair, mainly because if you Google around looking for research in aged care - - -

MS STEIN (ACG): There's an awful lot there.

MR MACRI: Yes, and it's an interesting journey.

MS STEIN (ACG): I'm really conscious of the time, so can I just gallop through a couple more things that we'd like to put on the table. I won't go into a lot of detail, but Peter has asked that I table the issue of bonds and the part payment of bonds and the impact that will have on capital reserves. We like the idea of the Australian Seniors Gateway, but we're not quite sure how it will be managed and coordinated. I think that's probably a discussion for another day, but just to - - -

MS SWEANEY (ACG): I guess with the gateway or with the CDC and the possibility of more consumer-directed care, we were wondering where it would be identified and the person eligible, is that the gateway who would say, "Mrs Smith is eligible for the dollars to go with the CDC." Then I guess the person then seeking services to support their needs, is that a risk for providers in the fact that that can be transferred?

MR FITZGERALD: Let me deal with that if I can just briefly, because it's helpful. The Australian Seniors Gateway is going to be the only way by which you can access entitlements to formal aged care services, however defined. Over and above the aged care services, there will be a range of services that are provided by organisations, for example, information, assistance and advocacy, social supports and social engagements, supports for carers, health and disability supports. So they're accessible differently. But if we're coming to community based care, residential aged care services and a range like that, this is the means by which you get there. You're absolutely right. A person will access that particular gateway through any number of ways, but they'll get to the gateway, a detailed assessment occurs and at the end of the assessment, a person walks out with an entitlement to a set of services. Absolutely under client-directed care, they will choose the provider and they have the ability to change providers.

So the funding now travels with the consumer and there is choice of provider and maybe choice of services that will travel with that. So from the provider's point of view, they no longer receive direct grants from the government, unless they are of those types of services that I've referred to. They will be reliant on consumers walking in their front door with their entitlements. So it changes very dramatically the way in which the services operate. In the community space, that means that there will be a lot of new providers and there will be a lot of providers that will extend their services beyond the very limited range of services they now operate.

On the other hand, it's possible that some providers will go out of business, they'll choose not to be in that market and equally with residential care, we're freeing up that as well. So, yes, it creates a dynamic marketplace for providers. But at the end of the day, you have to choose. Do we want to give choice to consumers or not and if we do, the funding travels with the consumer. Over and above that, there are a range of block-funded services that would continue. Community transport would be one example, advocacy would be another and we're just talking about things in relation to palliation and all those sorts of things. But that's how it basically works. The level of disruption to the market will really depend on each individual organisation, but it will be substantial. Effectively the HACC program gets merged into this and disappears as a program in its own right.

MS SWEANEY (ACG): I would support that. With the consumer-directed care, I guess that then flags that we need to be more flexible in work regulations, as well as regulations that govern our services now because I think just on consumer directed care, a lot of providers are fixed in a box because the guidelines or legislation provides it from going chopping wood or whatever it might be, but also with workers, if we now are funded for however many packages, it's guaranteed funding and if Mrs Smith leaves, we bring in a new Mrs Smith, but the worker, if she's doing 16 hours, we've got to keep paying her 16 hours?

MR FITZGERALD: You have to make a decision about community care as to what you think that the likely volume of clients will be. Most larger agencies obviously welcome this approach because they can see their business model increasing.

MS SWEANEY (ACG): I think it's excellent.

MR FITZGERALD: Smaller organisations are less certain, will they be able to attract a sufficient number of clients and consumers. I have to say that we understand the workforce issue. We think that is manageable. But the reality is either you give the choice and the budget holding to the consumer or you give it to the provider and we think that an empowered model is one where you give it to the consumer, with the exception of those block-funded services, of which there will still be quite a number.

MS SWEANEY (ACG): I fully support it. I just would like to see more deregulation around the work issues, because that holds us pretty tight now, workplace agreements and how we treat our workers.

MR FITZGERALD: I presume most of you are going to enter into enterprise bargaining arrangements which will have to deal with that, absolutely.

MS SWEANEY (ACG): I guess that leads to technology. I would have liked to have seen more about the use of technology and there's a decreasing skilled workforce and all of that and the wonderful technology around and how we can better utilise that into our services. As much as consumer directed care, I thought technology should be there and encouraged and providers to be using and supporting their services.

MS MACRI: We've actually had that message fairly consistently and we have been looking into and that will be further elaborated on in the final report.

MS SWEANEY (ACG): Wonderful.

MS STEIN (ACG): Can I just gallop home on three points. We're just a bit unclear about how educating carers - what sort of education in particular we had in mind there and, given the demography of some of the carers, would it be value added in the long run and how would you recognise that training and education?

MR FITZGERALD: Well, give us the other two points you've got and then we can deal with them all.

MS STEIN (ACG): We thought it was very heartening to see emerging special needs groups identified and we probably would have liked to have seen the homeless and refugees added to that. Casemix funding for palliative care is of a concern because of the skill base of most residential aged care and community care programs and it would take a huge infrastructural input to upskill existing staff to a casemix standard. So we only came in on the tail end of the woman before us but we would certainly endorse her comment about getting it into some preliminary service programs so people would be service-ready for palliative care.

MS MACRI: As Yvonne said, it could be a combination of casemix and block funding, or again we have - we went down the path because in terms of if you talk about increased care - I mean, people are saying ACFI is not reflecting adequately that end of life palliative care stage. We still are looking at how you add on or supplement, and for what period of time that end of life palliative care - - -

MR FITZGERALD: I mean, one of the questions we raised with Dr Luxford was, in a normal acute environment one can actually almost, with some certainty, say when palliation starts and maybe when end-of-life care starts. In aged care it's a much more transitional process. In one sense it makes no difference at all except until you want funding for it and I suppose the question we asked her was, when is there a noticeable increase in the costs of care for someone that is in need of palliation for end of life. So defining it is of no relevance other than if you then say, "We want additional funding or resources." I don't know if you have any insights into that. What we are committed to is trying to reduce the transference between residential aged care facilities and acute.

MS SWEANEY (ACG): It's such a waste of a resource.

MS STEIN (ACG): It's not a good place for people that require palliation, the acute sector.

MR FITZGERALD: Sure.

MS STEIN (ACG): With the right infrastructure in most residential aged care homes it will be accommodated.

MS SWEANEY (ACG): Everyone in high care is dying, so it's such a fine line. What I see now to even three years ago, people come, it's really short and they come in dying. So it's almost like there would just be a funding for end of life, but where it comes in and how you measure that - - -

MS MACRI: It's where that intensity is, though. Where does it become, from a funding point of view - - -

MS SWEANEY (ACG): If you're high, high care, there's not - there to pall care, there's not a lot of difference in - - -

MS MACRI: As we've said also, palliative care can be a lengthy process or it can be a very short one.

MR FITZGERALD: So any insights you have into that area would be helpful, given that you're in the business of it and you're a practitioner in this field. Have you got any other issues? I'm just conscious of the time and I want to make sure you've got your issues before we come back to a couple.

MS STEIN (ACG): I just wanted to talk about the Royal College of Nursing's scholarship program and that comes directly from DoHA. I think that it could be broadened and pick up allied health, pick up volunteers as a funding conduit to people that give freely of their time rather than restricted to nurses per se.

MS MACRI: If you start to go outside of nursing per se it may not be then administered by the RCNA, it may or it may not be.

MS STEIN (ACG): Well, perhaps they could tender for open brokerage or something but I just think that there's a small pool of people that are eligible and that will become saturated over time, even with the staff turnover.

MS MACRI: So rather than RCNA you're really talking about DoHA having a broader base in terms of allocating educational scholarships.

MS STEIN (ACG): And greater recognition through remuneration of the VET sector as a conduit to higher education.

MR FITZGERALD: Can I just bring up a couple of things very briefly because we are out of time. One is relation to the training of carers. Here we've been largely guided by the carer organisations around Australia who have indicated to us very clearly that we need to be providing a broader range or broader mix of services to, and supports for carers. So our proposal in relation to carer support centres would see those centres replacing some of the current programs but they would include the provision of emergency respite, what we would regard as peer support, counselling, advocacy to a lesser degree, but also some training. Now, I presume what we're talking about in terms of carer training, we're talking about very practical stuff about how you actually support the ageing person or the person with the disability, but we have not at all been prescriptive about that training. I would imagine it's very much about hands on.

MS MACRI: Some of it will be around manual handling, safe occupational health and safety practices, lifting, all of those sorts of things, but also just even some education around dementia and some of the challenging - - -

MS SWEANEY (ACG): Just the ageing process.

MS MACRI: - - - behaviours and some of the issues for which carers aren't equipped. So it's giving them some basics.

MS STEIN (ACG): I still would like to put on the table the fact of the demography, the ageing demography of the carers, and increasing expectations of them may not be realistic.

MR FITZGERALD: We understand that. In fact there are issues about just the relative numbers of carers going forward, as well, as a diminishing group of supports for ageing Australians. Again my point is in some senses we are guided by the particular peak bodies and so we are taking some sort of advice from them, but we do take account of the ageing. The other one I just wanted to pick up before we conclude is about the bonds. We acknowledge that, going forward, the ability of organisations to both offer a periodic payment or, at the choice of the consumer, an accommodation bond in a sense expands the opportunity for accommodation bonds but at the same time we're also trying to drive down the excessive bonds so they better reflect the actual cost of accommodation.

As you know, bonds today bear almost no relationship to the cost of the accommodation; they bear a relationship to your ability to pay them and maybe - maybe - the market but much less so that. So for organisations that have relied on very high bonds, yes, there will be some adjustments, but we think that they are manageable. Where the bigger problem occurs is where an organisation relies on the payment of a bond to the estate of someone who has died and the only way they can pay that is when they receive new bonds. So you've got this sort of cash flow problem. So there is a cash flow issue and we're conscious of that, and a number of the peak bodies representing aged care providers have raised those issues with us. It's all in the transition and we think that we have to be very careful about that transition and we're taking advice on that at the moment.

MS STEIN (ACG):   Anglicare Canberra Goulburn traditionally doesn't charge high bonds and so what applies to the top end of the market also applies to the bottom end of the market.

MR FITZGERALD: Well, you would be less affected then.

MS STEIN (ACG):   Well, we're less affected but it's still an issue.

MR FITZGERALD: Sure. Although I might say that it depends on whether you believe that consumers will continue to choose to pay a bond as distinct from a periodic payment. I think the answer to that seems to be emerging that most providers believe that a fair percentage will continue to choose to pay a bond rather than a periodic payment. At the end of the day each provider will have to make that assessment, but it seems to be an emerging consensus that not most but a fairly substantial portion of people will continue to pay a bond, but less excessive than the current bonds that are offered in some services.

MS MACRI: You will have a greater pool because of the amalgamation of high care, low care, so at the moment you're only getting bonds for your low care, so your pool broadens.

MR FITZGERALD: Thank you for that. Thanks for your points.

MS STEIN (ACG):   The report, we look forward to it.

MR FITZGERALD: We look forward to implementing it. Thanks very much.

MR FITZGERALD: Thanks very much. If you could, for the record, individually give your name, the organisation and position in the organisation that you represent.

MR WARD (PGA): Glenn Ward, alternate national councillor for the Pharmacy Guild of Australia, chairing the government relations and policy committee.

MS MAY (PGA): Khin Win May, national manager of policy and planning at the national secretariat of the Pharmacy Guild of Australia.

MR FITZGERALD: Good, thanks very much. I know we had a submission back in August 2010. I'm not sure whether we've had an update.

MS MAY (PGA): We sent a letter in response, so it's very brief.

MR FITZGERALD: That's fine, thanks for that. Yes, I've got it, thanks very much. So if you could just give your opening comments and then we'll have a bit of a chat. That would be great, thanks.

MR WARD (PGA): Certainly. On behalf of the Pharmacy Guild of Australia I'd like to thank the commission for the opportunity to address you on this matter of caring for older Australians as addressed in the Productivity Commission draft report. The guild, as you would be aware, represents pharmacists like myself who are proprietors of community pharmacies. You may not be aware that there's over 5000 community pharmacies spread throughout Australia providing an array of services which extend well beyond the provision of medicines. Services such as diabetes advice and management, medication management services such as medicine reviews, dose administration aids, medicine profiles, continence advice, supply of medical devices such as walking-sticks, toilet seat raisers, walking frames, wound care advice, home delivery services, all used by the aged in our communities. As such, pharmacies are often the first point of contact of the primary health care system for many people.

Let me first say that the guild commends the commission for identifying potential areas for reform that can meet the challenges facing Australia's aged care system in coming decades. The commission has made a number of key recommendations and we offer the following brief comments in response to the recommendations from the perspective of a community pharmacy. Our main concern is that the draft report and recommendations deal primarily with aged care issues within a residential setting, not adequately focusing on community based aged care support systems, particularly in the primary health care setting. As stated in our initial submission in August 2010, polypharmacy, resulting in alarming rates of medicine-related problems, often brought about by confusion through receiving medical advice from more than one medical provider, short-term admission to acute care facilities and discharge without adequate follow-up and support or the pervasive encroachment of diseases such as diabetes and dementia or the condition of incontinence are all major factors which impacts on patients' quality of life and often result in a longer-term admission to hospital and residential aged care facilities.

At this point I again draw the commission's attention to the current infrastructure and network of community pharmacy in providing primary health care services. Community pharmacists are cognisant of the special needs of older Australians and the need to provide and facilitate support services and longer-term strategies to assist in their ability to live independently in their local community for as long as possible before needing to move to residential aged care facilities.

Because community pharmacists are the most accessible health care professionals, many older Australians seek advice from their local community pharmacists. Generally speaking, Australians visit their pharmacy about two or three times more often than their GP, so the community pharmacist is in an ideal position to evaluate and refer to either medical or allied health providers. Because older people tend to use one doctor's clinic and go to one pharmacy, the pharmacy's dispensing records provide a reasonably complete record of prescribed medicines from all sources, GPs, specialists, dentists, optometrists or nurse practitioners. The community pharmacy is often the first point of contact in obtaining a patient's medication history for hospital emergency departments after crisis admission.

The guild urges the commission to recommend policies, systems and funding arrangements that also aim to support older Australians to live independently in the community, of increasing importance given the current environment for health reform. The lack of focus on community based aged care support systems is also noted with regard to the concept for establishing an Australian seniors' gateway agency. While we are supportive of efforts to simplify consumer access to information, assessment referral and care coordination, we are concerned with a lack of information on how the gateway agency is proposed to integrate with aged care, acute care and importantly, the primary health care sectors. This is in addition to the lack of information on how the aged care sector, both residential and community based, will interface with the acute and primary health care sectors, particular with the introduction of Medicare Locals from July 2011.

The need for coordinated multidisciplinary management of chronic illness and information dissemination targeted at preventative health in the community cannot be understated, nor can the need for greater liaison and coordination between health professionals, including community pharmacists, which should be promoted and encouraged. Whilst the guild agrees with the need to create a portal for knowledge of all the services available for older Australians, the problem is that as the population ages and often more isolated than in previous generations without the family structures around them, older people are not aware of the range of assistance available to them or their family. Community pharmacy, through its location in urban, rural and remote areas is ideally placed to be a part of this portal of knowledge, using everyday IT services.

While I have focused here on the community setting, it is important to note that community pharmacy is heavily involved in medicine management within residential aged care facilities. As you may be aware, residential aged care facilities are subsidised under an aged care funding instrument and, through accreditation, required to deliver appropriate management of medicines in line with quality use of medicines principles. To facilitate this, the use of dose administration aids in this setting should be considered best practice and made mandatory for all accredited facilities. To support this, there should be adequate and quarantined funding for residential aged care facilities to ensure that best-practice medicine management and quality use of medicine services are in place.

On the topic of dose administration aids, I feel it's important to bring the commission's attention to the important role this service has within a community setting for older Australians. Dose administration aids support at-risk patients and/or their carers to better manage their medicine with the objective of improving adherence, thus hopefully avoiding medicine misadventure and associated hospitalisation. Dose administration aids also provide a living record of actual doses taken by the patient, not just what has been supplied. This provides useful information for the doctor, pharmacist and nursing staff to assess the patient's adherence and consider any identified problems. The DAA service is labour intensive, requiring significant professional input from the pharmacist who has been absorbing the costs in providing such a service, mostly because of their professional and community responsibility.

There would be significant benefits to the government and to the patients and their families to fund dose administration aid services as part of the current government program, such as community aged care packages, extended aged care at home and transitional care programs. There may also be cost benefits in financing them in the community for aged people deemed at risk of medicine misadventure under appropriate PBS arrangements. This would result in a level of care equivalent to the scheme provided under the Department of Veterans Affairs dose administration aids funding which was introduced in 2008. Under this scheme, the community pharmacist receives payment for the service and its review to ensure the DAA service remains appropriate with ongoing coordinated care provided by the GP and pharmacist.

In conclusion, the guild recognises the enormous challenge for government to provide adequate, efficient and quality health and aged care services due to the increasing proportion of the older population in Australia. The guild's view is set out in greater detail in our submission. We welcome any questions from the commission relating to the role played by community pharmacy to assist older Australians.

MR FITZGERALD: Good, thank you very much for that. Can I just start on the community based one. The commission is very conscious of the fact that the vast majority of services to older Australians will be provided through the community. In fact, by 2050, three million people will receive services through the community and only 600,000 will receive them through residential aged care. So in a sense the whole of the system is actually designed to try to take account of that very significant shift and growth. I'm a little bit surprised that you thought we hadn't paid enough attention to the community based aged care support systems. But I think what you're really saying is the linkage with the primary health care setting is the issue that you've raised, because I think we've done a reasonably good job of recognising this huge shift and growth in the community based aged care system.

You raise the interesting issue about the linkage with primary health care and in particular the introduction of Medicare Locals. I want to throw it back to you, if you've thought it through, what you think we need to say about those linkages? We can about the linkages, but we're not sure what the Medicare Locals look like just yet and it may be you don't either. We are very, very happy, in the final report, to actually be more robust about how the aged care system, these Medicare Locals, and Local Hospital Networks would work, if we can get a handle on exactly what they look like. One of the things we're being very clear about is we're not trying to link our reforms, necessarily, to health reforms unless they're appropriate. Anyway, your views, because this is a tricky area - and I'll come to the gateway and we'll come to residential aged care. But have you got particular ideas as to how we can better link the delivery of aged care sector with primary health care?

MR WARD (PGA): I have specific viewpoints, from using IT and from 25 years' experience in community pharmacy, and a lot of that servicing aged care; that is, that a lot of readmissions to acute care facilities, a lot of costs initially from the community into acute care facilities, happens through a lack of communication. In this day and age, with IT as it is, if local hospitals were resourced adequately with the communication gateway, if aged care facilities were resourced with a communication gateway, GPs and pharmacies, there'd be no excuse for any lack of information.

We have facilities, in my area, of people being discharged from acute care facilities on a Friday afternoon to free up beds, being left on their front doorstep with no-one to care for them and no-one even knows that they're there. In this day and age there's no excuse for that. Obviously it all comes back to funding. But if there was some way that this could link in with aged care and the community packages, there should be a cloud situation where this can all be accessed from every provider.

MR FITZGERALD: I take on board your point about the community pharmacy being a good point of access for information and there's no reason at all why the gateway, going forward, wouldn't want to use GPs, community groups, and community pharmacies as a portal for information, and there's no reason why that couldn't occur. But you're actually talking about a much more interactive system, are you?

MR WARD (PGA): Yes. Community pharmacy is the same whether you're in Hobart, Cairns, Broome, or Karratha. We all are online; that is what Medicare requires us to do these days. We all have ultra-fast broadband, all our dispensing histories go straight into Medicare's computer in real-time. There's no reason that can't be used for this exact same communication. There isn't a Medicare office in many of these places. I know in my suburb in Hobart there is no Medicare office. People can't access this information; the people that we're talking about aren't that IT literate that they can google things themselves on the Internet to find out what services are available, but they attend their local pharmacy.

MR FITZGERALD: But do you see yourself, as the local pharmacist, playing a supportive role in terms of helping older Australians to access the gateway or other services, or do you see it predominantly as an information portal? I just want to understand a little bit, because there are levels to this: there's the information itself, then those things that are supporting people to actually access particular services - in this case, the gateway - and then of course we actually move into assisted decision making and those sorts of areas. I was wondering whether or not, along this continual support, before you even get to the gateway, where you see the most effective role of the community pharmacist, and then we'll talk about what happens in the access to services.

MR WARD (PGA): Initially just in the portal of knowledge and the facility to whatever that you came up with for these information services, as I said, because we've got the IT infrastructure there. But there's a huge capacity to expand on that, but it all comes back to funding and what could be delivered at the time.

MS MAY (PGA): Pharmacy can also refer people. When they do a printout at the pharmacy then, depending on what the condition is or what kind of a requirement they have, they can do some quick intervention and then refer people to necessary services, if they have information that they can use to refer them. So I think, in the terms of continuum, it is first information and also referral to appropriate services; providing advice and things like that.

MS MACRI: Just in terms of the community care - take residential aged care out from it - because, whilst it's not perfect, I think there's at least a relationship between the residential aged care facility, the pharmacy, and the doctor, to a relative degree. When you get out into the community, it's quite different, and that's where the predominance of care is going to be. I agree with you in terms of the dose administration aids in relation to people in the community and safely giving that medication.

I just wonder how many people perhaps don't connect with one local pharmacy, but - the suburb I live in, I think there's five in the main street - whether people shop from pharmacy to pharmacy. I wonder about those relationships when you talk about primary care and the relationship with the pharmacist, whether it's clients. Because we've seen that break down with GPs a bit, with these super clinics now where people are purely and simply numbers. They're in and out, it's not like the good, old, family GP practice; it's changed a lot. I'm just wondering whether that's changed in those relationships between the doctor, the pharmacy, and the patient, through these super clinics and people shopping around different pharmacies.

MR WARD (PGA): Our research still definitely shows that it's a much more relationship issue. Whether there's five on the one high street, the younger generation definitely will shop on convenience; the older generation that we're talking about are creatures of routine.

MS MACRI: Right.

MS MAY (PGA): We did research some years ago with the consumers and it showed about 80 per cent tend to stick to one pharmacy, but that was a few years ago.

MR FITZGERALD: With the advent of the e-health system, assuming it gets up - and we are assuming it gets up - we are looking at how we link in aged care information into that system. But is it proposed in the new health arrangements that pharmacists, for example, would be able to access the pharmaceutical records of a particular patient or is this going to be exclusively to the GP? Where would you fit within that electronic information?

MR WARD (PGA): It depends on the patient's consent, but, yes, the same of any other non-prescribing GP, they'd be able to access from the patient's chip on their Medicare card, whether or not approval had been given. But if they were attending the same pharmacy, we've got all of that anyway.

MR FITZGERALD: You've got all that anyway. Again, just in relation to the community, before we discuss residential, you mentioned our recommendation about locally based, visiting, multidisciplinary health care teams. It's a particular passion of mine that we should look at and explore the opportunity for the development of these multidisciplinary health care teams. These would certainly work in harmony with GPs and so they're not a replacement for them. But it does seem to us in the aged care area, as you've identified here, that there does need to be a body of expertise working together in the local communities, which have some benefits.

Where do you see the role of the pharmacy in that? How do you see that? If we were to see an expansion of these teams - and they're very costly to establish and they're by no means going to be rolled out quickly, do you see any particular implications in relation to the pharmacies?

MR WARD (PGA): Nothing more so than every aged care facility it's a recommended standard that there is a medical advisory or clinical advisory committee that will operate with at least one pharmacist on there now. That would just be an enhancement and a larger-type situation. Even if there's multiproviders within the one area, there would still be representation from a few but you'd still be working on that multidisciplinary board and that's what we're recommending that it would only enhance the communication and therefore the care, provided whether they're in the community or a residential aged care facility having that.

MR FITZGERALD: You may not be aware of any examples where these teams have operated successfully. There are some teams around but very few. Have you had any experiences good, bad or indifferent?

MR WARD (PGA): Not personally, no.

MR FITZGERALD: Residential aged care. Sue, do you have some - - -

MS MACRI: I was looking at your submission and DVA does subsidy the unit-dose packaging for community but there's no other subsidisation for people outside of the DVA.

MR WARD (PGA): No, and that's what I've put in my statement today. That's a hugely successful for the dose administration aid but for the service to the client. From my own person experience there's a large DVA area and even though most pharmacies will only charge between three and five dollars a week for a DAA people will baulk at paying such a small amount. As soon as it's provided free to them, they will readily get the communication from the GP. It has to happen on a referral from the GP who, in all situations, are only too keen to provide that and then that provides six months' worth of dose administration aid to that veterans affairs person. We've had huge success with that.

As I said, it's a living document because even though we have a record of what - and the doctor has a record of what he has prescribed, we have a record of what was supplied but you're not in their kitchen cupboard seeing what they have taken. We provide home delivery service to a lot of DVA people and you can see that immediately and we can communicate with their GP. So the GP is prescribing on correct information, not on what he presumes they're taking and gives a much better life outcome to those people.

MS MACRI: Do you have any idea in terms of costs or has the guild been to the government around the rest of people receiving community care and the inherent costs in taking that out to the broader aged community?

MS MAY (PGA): There was some research on the DAA itself, how much it costs for community pharmacists in the community and also residential. I haven't got that in front of me but I'm happy to send - - -

MR WARD (PGA): Costs to the government to wind that out to age pensioners.

MS MAY (PGA): Not the funding model as such, no.

MS MACRI: Why has the government baulked at it not going out? Has it been put to the government? I mean, I'm familiar with the system and I endorse it.

MR WARD (PGA): For the costs of lots of other medication this is a negligible cost and, as we said, if appropriate PBS guidelines put there - and presumably, without thinking too much on it, those receiving dementia or Alzheimer's medication would be the primary guideline for that - it would not be, in the overall scheme things of the PBS, let alone the health budget, a very big cost at all.

MS MACRI: Yes, because it's just such a safe - - -

MR FITZGERALD: Just taking that forward, in the letter here you say that you believe that we should recommend that dose administration aids should be mandated for residential aged care facilities. Is that different?

MS MACRI: That's different to what - well, the aid is the same but the community - in residential aged care they can either have the unit dose or they can still be using traditional - - -

MR WARD (PGA): The majority do use dose administration aids. They follow best practice. But it comes back to a cost. If the provider is on a knife edge as to whether they're going to survive or not, an extra few thousand dollars over the whole year they look in the short term, whereas if there was quarantined funding that came specific to quality use of medicines, using for dose administration aids, then they couldn't baulk at doing that.

MS MACRI: At the moment the cost goes not to the resident, it goes to the provider of that pharmacy service. Is that what you're saying?

MR WARD (PGA): It's all under ACFI funding at the moment and then the home decides how they want to charge - - -

MS MAY (PGA): Use that funding.

MR WARD (PGA): There is a contract with the pharmacy to the home and there is a cost in most situations to the home to freight that.

MS MACRI: Who meets the cost at the moment? Not the resident, the home?

MR WARD (PGA): Yes.

MR FITZGERALD: Sorry, can I just understand this. Are you saying that ACFI doesn't cover that cost or it does?

MR WARD (PGA): No, it does.

MS MACRI: Is there a specific component within ACFI? I don't recall - - -

MR WARD (PGA): One of the standards is about quality use of medicines.

MS MACRI: That is in accreditation.

MR WARD (PGA): In accreditation, yes. But the homes are funded through ACFI.

MS MACRI: But ACFI is around the instrument and around care. I don't recall ACFI having specific - - -

MR WARD (PGA): No.

MS MAY (PGA): So they can decide how they spend that.

MS MACRI: I think there is a little confusion there because ACFI doesn't actually fund medication - - -

MR WARD (PGA): No.

MR FITZGERALD: Just so I can understand this. You're saying that the DAA should be mandated for accreditation purposes but are you also saying that it should be funded as well - - -

MR WARD (PGA): Yes.

MR FITZGERALD: - - - separately?

MR WARD (PGA): And the funding quarantined so that can only be used by the home for - - -

MR FITZGERALD: But what you're saying is many residential aged care do use DAA but they're not separately funded?

MR WARD (PGA): It comes out of their general revenue.

MR FITZGERALD: Okay.

MR WARD (PGA): The other one that we started on was EACH and CACP and EACHD and the TCPs. CACPs generally don't pay for a DAA. EACH do and TCP is dependent upon the agreement with the pharmacy. So, once again, funding in that should be, we feel, the best practice so it should be funded.

MR FITZGERALD: Right, okay. Other questions?

MS MACRI: No, not really. I think the whole area around polypharmacy and poor discharge information is an issue for residential aged care and community care providers as much as it is for pharmacists and other - - -

MR WARD (PGA): For the years the federal government has been talking with hospital funding that we'll get better communications on discharge but you still end up with the same.

MS MACRI: Are the pharmacy reviews still occurring in residential aged care where the pharmacists would go in and do - - -

MR WARD (PGA): Yes.

MS MACRI: Does that occur for all residents or all homes or all pharmacies involved in that or is it something people elect to do or not do?

MR WARD (PGA): No, the homes enter into an agreement with an accredited provider of medication reviews and all beds within the home are funded for that. But it's a case by case review basis now. Initially it was just one review per bed, per year. Now, it's normally a collaborative review from the GP requesting it to the pharmacy but it's still all funded through Medicare.

MS MACRI: Can the nursing home, if they're concerned about a GP's prescribing habits - - -

MR WARD (PGA): Absolutely.

MS MACRI: - - - initiate a pharmacy review

MR WARD (PGA): So generally from our practice it's all new admissions and then on advice of the RN as to prioritise other reviews.

MS MACRI: Right.

MR FITZGERALD: In your submission you talk about a number of options in relation to residential aged care facilities. You have Option 5, "Collaborative prescribing nurse practitioners." I'm not expert in this - and Sue is - but can I just understand this at the moment are nurse practitioners able to prescribe drugs at all under the state and territory regulations?

MR WARD (PGA): Yes.

MR FITZGERALD: They are?

MR WARD (PGA): Yes.

MR FITZGERALD: So this option here that you refer to in your previous submission, the intent of that option is to achieve what? You don't have to respond to it, it's probably in the submission. But I just notice on page - it hasn't got a page number on it but it's in the options at the back of the submission, option 5 - - -

MS MAY (PGA): I don't remember we putting in our - - -

MR FITZGERALD: Don't worry about it.

MR WARD (PGA): Not on mine.

MR FITZGERALD: It's in the document - sorry, yes, this may have been to another inquiry but you've got: "Submission to the review of the existing supply arrangements of PBS medicines in residential aged care facilities and private hospitals - January 2009." You've attached it to your submission but it's another submission.

MS MAY (PGA): Yes. We refer to the previous submission about review of the supply but I think these are the options that were put through but then I think there was a recommendation made out of that that the medication chart becomes a PBS prescription.

MR FITZGERALD: That's correct. Has that been adopted?

MS MAY (PGA): That's being worked through. I think that's been adopted by the government and I think as part of the Fifth Agreement it's being worked through.

MR WARD (PGA): In consultation and trial stages. So in the next couple of years we'll be hopefully heading towards that.

MS MACRI: Can I just ask one very quick one. The drugs and poisons acts, or the derivation of that in each state and territory, do they differ enormously?

MR WARD (PGA): Not enormously, no. Through COAG they're trying to bring that all closer together.

MR FITZGERALD: Thank you very much for that. Thanks for raising those issues and we'll see where we go to with that.

MR WARD (PGA): Thank you very much.

MR FITZGERALD: Could we have the Federation of Ethnic Communities' Councils of Australia. If you could give your name and the organisation and the position you hold within that organisation that you represent.

Certainly. My name is Pino Migliorino. I'm the chairperson of the Federation of Ethnic Communities' Councils of Australia.

MR FITZGERALD: We've had lots of submissions from members of your organisation in various states and territories - very much welcomed - and a number of providers as well. So we've had a good dose of responses to our report from the CALD communities but we're very keen to hear from you today.

MR MIGLIORINO (FECCA): I think that's interesting, too, because in terms of the original submission basis for the report there were probably far fewer and it certainly was a concern, and it goes to pretty much the heart of the first point I want to make. I won't go through the data; I think the data is pretty obvious and you've probably heard it a thousand times. The reality is that with the proportion of ageing who are from non-English speaking background there's not a commensurate level of either advocacy or representation in various formats or decision-making and it's something I wanted to bring to the attention of the commission.

I think it's very, very important that, given the way that government funding has gone and the proliferation of more community based service provision and, to some extent, the wane of institutional care or residential care in ethnic communities in terms of some of the issues around the maintenance of that, that there are literally hundreds and hundreds and hundreds of organisations, yet they don't form either as an industry or a sector and they certainly don't have a voice. As chairperson of FECCA I also represent - and I see it as an onerous task - this whole range of issues in various government forums and structures like the Ageing Consultative Committee and I really do feel and really strongly state that there is not enough voice in those ongoing structures.

With that I just wanted to touch on the key parts of our submission and from that then obviously be available for questions from you. Your comments about the level of participation most recently are taken on board and I think we have been very keen to make sure that we did push that and certainly been working with a number of state-based organisations and other industry-based organisations. Part of the reason was to some extent the response to the draft paper, in that while - again, maybe as the reflection of the lack of input - the draft paper was very specific in identifying the fact that Australia needed to acknowledge and react to cultural diversity, but then there was very scant attention to that issue through the rest of the paper. So without going into why I believe that happened or not, there are three overall comments and then I wanted to make a series of specific recommendations.

Firstly, the opportunity to talk about caring for older people is absolutely timely. We're not allowed to use words like "tsunamis" or the "ageing in the population", this, that and the other, but the reality in ethnic communities is this has been a very, very big issue. Also of interest to us has been the fact that we've always been a little bit out of kilter from the prevailing government philosophies or policies. If we go back to the period of the 80s and 90s under Don Grimes where there was that whole push to de-institutionalise aged care, the impact on ethnic communities was a removal of funding for nursing home accommodation at a time where that was exactly the type of care that they required.

What's really interesting now is that the type of scenario being depicted by the Productivity Commission where residential care tends to be almost end of life or high level dementia is exactly what has been happening in many CALD communities and CALD community facilities, but what is of interest is that the community care or family-based care before was not being subsidised whereas now I think there's a great sense of keenness, if you like to make sure that when the die is recast and we refocus on community care, that ethnic communities are considered in the middle of that because there is a need to actually backfill what has been a long-term issue in that community.

So in terms of the report we obviously welcome it. There are so many really strong things which are commensurate with what we've been saying in terms of the flexibility and service delivery, increased equity, notions of dignity, affordability, accessibility and so on. I think what's really important for us is finally an acknowledgment of informal carers. It's certainly been an aspect of aged advocacy but in ethnic communities it's never been articulated the way it is now and I think that's highly commendable.

Our concern around the draft report centred on the limited recognition and focus on diversity through the document and to some extent the inclusion of CALD as a special need category - I think it's chapter 6 - and then putting it with GLBTI has to some extent annoyed the sector more than anything else, (1) in terms of what does "special" make, and (2) how do you lump in such disparate - - -

MR FITZGERALD: I can assure you if it annoyed you it certainly annoyed the gay, lesbian, bisexual and transgender groups as well.

MR MIGLIORINO (FECCA): That's not to say they don't cross over in many situations.

MR FITZGERALD: We take on board that that is - I'm not quite sure why it occurred but we do acknowledge absolutely the differences between the CALD community and the gay and lesbian communities as well. So we do acknowledge that.

MR MIGLIORINO (FECCA): Yes, appreciate that. To some extent it picks up some of the thematics around the area in terms of one of the real issues, especially when the two issues cross over, is the alienation of family in the care of older people, especially around sexuality issues, and I reckon it's a really complex one that does need to given consideration. I think the issue for us then is a sense of what we'd like to see a lot more of - and there certainly is a series of recommendations - is a far better integration of the issues of diversity and impact on system that that diversity provides right through the report.

We obviously commend a couple of areas in the draft paper; of particular interest is the workforce shortages and informal carers. I think it's almost become an anachronism now to talk about ethnic-specific nursing homes speaking a language or being from a culture where the reality is that very few actually provide services either linguistically or from a cultural background. Certainly the context of the delivery in terms of whether it be religion or food is able to be met but the big issues in terms of who staffs the organisations and - I think a lot more needs to be done. In our paper we've recommended two areas; one is the whole area of vocational education around this area but the second one, one that hasn't been touched on previously, is particularly looking at whether this is a skill shortage area which should be part and parcel of an immigration discussion in terms of skills categories for overseas migration.

MS MACRI: I think one of the issues around that too, and has come out, is the reluctance sometimes from some of the CALD communities in terms of encouraging young women specifically to go into nursing or those caring roles.

MR MIGLIORINO (FECCA): Yes, that clearly is acknowledged.

MS MACRI: So that becomes a difficulty around the linguistics, the cultural, integration between residents and the people providing the care, and that's come through quite a few of the - - -

MR MIGLIORINO (FECCA): It does set up a particular issue if there's an expectation around that. I think there are so many issues around residential care I didn't want to concentrate on that but I think the reality is that the model which has received funding for such a long time is now quite questionable. I'm not quite sure if you've received evidence from New South Wales where the Scalabrini group of homes has been handed over to Catholic Care. That is quite an extraordinary event. If the Italian community, which is seen to be an established and resourced community, can't sustain health based infrastructure, then what does it mean? Certainly in our paper we picked up what does that mean for smaller groups, and I think a lot more thinking needs to happen in terms of the funding models and how we actually package up principles for beds around specific ethnic community considerations.

I suppose then it goes back to, in terms of our paper, there are a couple of really strong facts around this area. One is that there is a lack of a policy framework around ageing generally and aged care in particular around core communities and that does need to be addressed. Certainly there has been a marked difference, which was about five weeks ago when Chris Bowen introduced the policy on multiculturalism. The Department of Health and Ageing is now making different types of approaches and considerations. I do think there is going to be a lot more fertile ground, but I do believe that we actually need policy frameworks to address some of these issues, otherwise we will forever be trying to catch up.

In terms of that then, there does need to be some resourcing of the networks. I would have wanted probably for FECCA to have a far more substantial piece. I chair a committee for Alzheimer's Australia, a cross-cultural dementia network. The ability to be able to create really good input from that sector is absolutely laudable. I was envious or what was able to be done, compared to how hard we had actually tried to struggle. I do believe that in the systemic sense, there needs to be a lot more capacity around being able to articulate and work with the diversity and the impact the diversity has.

There are a number of areas in our recommendations. I think we've basically ended up with 17. Just to summarise them, I do believe that we need to centralise the notion of cultural diversity within the whole aged-care planning. It tends to affect the whole system of both ageing and aged care provision. I won't go into too much detail, but suffice it to say with the huge numbers and the particular nature of language and culture in the ageing years, it does need to be considered. It is really interesting, a whole integration debate which is presently taking place in Australia.

The actual evidence around ageing stands in stark contrast. You would have received input from DutchCare and I'm not quite sure of German care, but even communities which have for so long been seen as the epitome of integrated communities around the aged care environment, tend to want to have culture and language accommodated, far more than in any other aspect of their life and I think it does actually create a premium in this area. There is a real sense and a concern that the framework itself needs to include a statement about recognising cultural diversity as a core aspect of how we deal with aged care. Obviously - and you would have heard this from a number of people - the notion of gateway tends to cause concern in terms of a lack of definition of how gateways are able to or are competent in dealing with diversity or pathways which - you can take that analogy anywhere, but the reality is that there does need to be a consideration of vastly different starting points and different passages or paths to that gateway.

So there does need to be a very big amount of thinking around how the gateways actually work. Certainly the pressure on ACATs in the past and the model that they have been both lauded in terms of what they are able to do, but stressed in terms of their lack of capacity in terms of the numbers is a very, very good example to consider in terms of what then are the issues and do you build the incapacities in that gateway which deal with majority groups, because that will tend to be the case so you will tend to get Greek and Italian and Serbian and Croatian expertise. What about the small numbers, but quite specific numbers in other communities?

MR FITZGERALD: Can we just talk about that for just a moment. The first thing we endeavour to make clear in the final report which is not clear in the draft is that we acknowledge absolutely that there is a range of services that are provided outside of the formal aged care system which is necessary to enable people to access even the gateway. So the funding of information, advice, advocacy services through ethnic-specific peak bodies and what have you is important to the provision of social supports and social integration type services are all there.

So we acknowledge that for even people to be able to access the gateway, the support services delivered by a range of organisations will continue to be needed, which we haven't made very clear in our draft report. One of the issues however in relation to the core community is that there is an enormous number of organisations that exist and are funded. You've raised that issue. Because you actually deal with a huge number of issues across particular demographic cohorts, it makes your job and other people's jobs very hard. So I think the issue going forward is is there any way at all by which that can be rationalised? This is not an inquiry into the funding of peak bodies or support bodies for the core communities, but I think there is an issue that needs to be raised at some stage about that. So what is the best way by which the government can support people from ethnic backgrounds in connection to the general supports for the ageing community, but in particular in relation to the gateway.

MR MIGLIORINO (FECCA): It might sound selfish from our perspective, but obviously FECCA right now is in the position, maybe because I also have an expertise around ageing issues, to drive that. It's not been the case in areas of disability or women's issues or youth issues where national networks are developed. So you've got again an anachronism in terms of a huge number of individual organisations, but nothing actually bringing them together. I believe that that has got to be part and parcel of the approach.

MR FITZGERALD: If there was some way to actually say there's an aged support network of ethnic community organisations, it makes it easier for the government to be able to deal with that, but that's not the real issue. The second issue in relation to the gateway - and if I can just talk about some of the submissions - a number of the submissions that have been put to us have been very clear that simply having interpreter services is not sufficient and I think we agree with that. What we need in the gateway, as you say, is a cultural competence, but more importantly, we need people that not only can speak the language, but understand the culture.

If you look at this gateway, we were going to operate it at regional levels right throughout the country. But that creates a slight problem, because there is not enough people with both language and cultural experience and expertise to put in every region. That is clear. So a thought bubble has emerged, but it's only a thought bubble, and that is, apart from having the regional networks of the gateway, is can you almost have a multicultural gateway that exists maybe at state level or broader areas where you can actually have within that this expertise.

You're right. The major communities are not a problem, but the smaller communities absolutely are, of which there's an emerging group. So I'm just trying to work out a way by which we don't just simply say in the regions, if you don't have a bilingual speaker, you use interpreter services. Is there a more creative way by which we can actually service the core communities? It's almost having a region not based on physical locality, but a region based on something else. But I don't know. It's a thought bubble and we haven't discussed it internally.

MR MIGLIORINO (FECCA):   It's a really interesting one because it goes to the heart of the demographic mix and modelling around that. The thought bubble might be a thought bubble, but it does actually to some extent require a locality or a regionality base. So in terms of the way aged care services have proceeded, certainly the larger-scale communities are Greeks and Italians. I was part of it. I was with COASIT for 22 years and developed the whole aged care program there as a volunteer. You're able to work within those systems. Where it was large numbers, you were able to go cross-regionally, so you were able to pick up ethnicity and identify it across the board.

Once you start talking about smaller numbers, then that capacity becomes fraught and there are some really interesting models now. The one I would commend to you is at Fairfield, the Cabramatta Community Centre. It's developed an aged care capacity. Predominantly that's been made available by CACP funding and various other packages, and I think they're moving now to EACH and EACHD. But what is really interesting there is they're actually creating the notion of an ethno-specific service which mixes language and culture around a body which says diversity is what we're dealing with and so how do we replicate what an ethnic-specific agency would do on a multicultural format. It's been a really interesting one. In some recent funding in the southern area of Sydney, there was some CACP funding and COASIT, the Italian welfare organisation who runs a number of these programs, got the gig.

What was really interesting is there was a great deal of conflict with the local service providers and you had this ethno-specific coming in, but there are very few Italians in Sutherland. But what won was not because they're Italian, it was because they actually understood the nature of language and culture in service delivery. So if you replicate the componentry in that service model, then it will actually work. I think what has not been understood in this sector - and I think it's a really valid thought to take up - is language and culture are an initial barrier, they aren't an essential component all the way through the aged care program.

So if you take home based care and domiciliary care, the whole package around both HACC and CACP, there are really good, growing examples where language and culture have created the capacity to understand the service and receive the service, but over time the service value started to outweigh language and culture, to the point where that service could actually continue without it necessarily being done in language. I think there is a need for a more sector-wide approach, I think there is a need for a rationalisation. I don't think we can actually afford an ethno-specific modelling, because there are far too many groups and there's not enough, both, expertise and ability to pick up funds.

I presented to the Aged Care Standards Board at a dinner and someone said, "You're promoting ethno-specific services, but they're not going to work," and I think it's a really interesting point. What ethnic communities can provide is that initial - the cultural validity and the ability to actually create the capacities in a service to make sense and to be legitimate. It also provides specific links into a community, so it's a fantastic marketing approach, because you've got a defined market or a defined set. What's missing is then the capacity to run institutional or residential care. We should be looking at models which actually bring those two components together.

MR FITZGERALD: I think, from our point of view, that the gateway becomes very important, because we cannot allow the gateway to become a barrier. On the other hand we can't unrealistically believe that we can provide 130 services that speak - not only bilingual operations around the countryside. So I think that in terms of the gateway we're very conscious of the representations that have been made to us and they are very clear: they are just saying interpreter services isn't the way, we've got to do something different.

When you come to the actual services; as you know, this scheme works on the basis of an entitlement which the consumer then takes either to a community based organisation or referral to a residential care. Here we think that the ethno-specific groups have real opportunities to actually develop the services that are specifically attractive to various ethnic groups. But it may mean, in order to make them viable, they've actually got to work in partnerships with either non-ethnic-specific groups or other organisations, so that you get scale and scope of activity. In a sense, that's not up to the government to design and we don't see that as occurring, but we do see that they might have a facilitating role where, as you say in the Italian, Greek, and emerging Vietnamese and Chinese communities, they will have the scale to be able to operate their own services.

MR MIGLIORINO (FECCA): Can I respond?

MR FITZGERALD: Sure.

MR MIGLIORINO (FECCA): I think that is an absolutely legitimate way of looking at this. In a round of CACP funding two years ago, I brought together an aged care provider in the Macarthur which was multicultural, an Italian provider out of COASIT, and the Fairfield providers, and there were a nomination of Italian packages. I put together a model which was cooperative based, which would allow both options as well as legitimacy and competence right through the model. The Department of Health and Ageing only funded COASIT. So while you're saying that the government can't do certain things, it has an enabling capacity in terms of how it actually sets up the parameters around these partnerships. I believe a lot more innovation could take place if it was actually allowed to happen.

MS MACRI: Under the new model we would suggest that is the case.

MR FITZGERALD: You'd be able to do what you like, provided you're able to attract the community with their entitlements into the service, as distinct from what we've got now where the government - you tender and you get X number of packages. Under our model, as you know, that disappears. So I think there's scope for much greater - - -

MS MACRI: And you qualify as an approved provider under whatever the principles are for that, which will probably be fairly similar to what they currently are.

MR MIGLIORINO (FECCA): It's important for the existing services. It's also important for some of the more important informal care, and I was involved in the discussion of Alzheimer's around cashing in certain - especially the respite provisions and consumer directed care. A lot of that makes a heck of a lot of sense. There needs to be some development of infrastructure around that and also capacities around that, but it makes a heck of a lot of sense. It is a really important area.

MR FITZGERALD: But the other thing is, if we just take it to residential care, we've got your recommendations and I don't want to divert you from your main point - - -

MR MIGLIORINO (FECCA): No, I'm happy to discuss.

MR FITZGERALD: We are going to run out of time. It certainly is clear to me that there will be ethno-specific residential aged care facilities; there are now and there will be into the future. For the smaller communities, again, I don't think it's up to the government to decide what it looks like, but it may well be that you've got a Dutch wing or you've got a Greek wing in a particular service. But, beyond that, you're going to have clusters; you're going to have half a dozen people of a particular language group, whether they're Serbian, Ukrainian, or whatever it might be. I think they pose more interesting and complex issues, because even in a wing you've got enough scale there to be able to employ staff. I think the issue for us is the smaller groups or in fact the individual. How does a residential aged care service adequately deal with that, I think is tricky.

MR MIGLIORINO (FECCA): Yes. There have been a number of attempts to do that. There was a New South Wales clustering project, which was exactly that, utilising the aged care assessment teams and doing that. That took a fair bit of work, because your actual end product took a huge amount of input, both in terms of the role of the ACAT, the role of the support organisations, structuring visiting programs around them, structuring partial foods. Because part of this is, what makes something ethnically diverse or unique that actually starts being part of the mix. But fundamentally the provision of aged care - and bringing it back, because the discussion now is around those individuals. The greater value will be in actually engaging with communities and families and informal carers, because that's going to have a far greater impact.

I suggest it again: right now, in many communities, the only people who actually finally go to nursing homes are those where the level of either dementia or care is such that you can exonerate personal guilt. That sounds a big statement, but that's the way it's expressed to me. I'm hoping that my father dements, because then I won't feel as bad when I have to make that move. This notion of a residential aged care as a legitimate other is non-existent in many communities and I think we have to really understand that. If that's the case, then what then is the involvement of both families and informal care as part of that.

MR FITZGERALD: Just taking that statement, do you see that the shift in acceptance of residential aged care may well be dementia itself? We know that, in the general population, the majority of people in residential aged care facilities are and will be people that have substantial issues relating to dementia.

MR MIGLIORINO (FECCA): Absolutely.

MR FITZGERALD: But you think the CALD communities will be more willing to see their relative transfer into that facility if they have dementia, rather than if they're simply medically compromised?

MR MIGLIORINO (FECCA): I'm going backwards: that is why they've allowed it to happen. If you actually spend any time in these residential care facilities, especially the high-care wings, they are predominantly high-level dementia. Where there's a physical incapacity; there is a specific case I'm very aware of, a double amputee. It was an atrocious situation, because the way that the patients and the residents were treated in that ward was, "We don't have to worry about them," and the person who was of sound, full mind with strong physical impairments was going through a living hell. Any notion of individual outcomes or standards around that patient's care just went out the window, because it didn't accommodate the flow of that institution. So I think there's some really big issues there to address.

We've gone very broad in our approach as well, because certainly residential is important, but there are so many things which lead up to that. There is an absolute lack of appreciation in planning for later life in the communities, other than making sure you've got your mausoleum or your vault. It's really this sense of, "I've taken care of what's going to happen after I die, because I don't trust the kids, because I'm not going to be around. But while I'm around, they're going to take care of me." It's a really interesting set of discussions. In a number of presentations I've made, people say, "Well, what's the difference between ethnic groups or the general population? Because the second generation, the generation caring for older people, is the same." The difference is not that the level of care or the level of love is different, but in many ethnic communities the expectation is not a duty of care but a duty for care. The expectation is enormous that the person, whether it's a wife, spouse, or daughter, is going to be a carer, and it does have quite significant impacts on that family.

MR FITZGERALD: You've raised the issue of carers. I'm not sure if you've specifically made a recommendation about that. As you may or may not have picked up in our submission, we're talking about the development of national carer support sectors which would provide a range of services to carers, carers of people that are ageing, people with disabilities, people that have got mental health conditions and so on, so a generic sort of service. Again, it is important that they are able to support members of the core community. The question again there is whether or not you need ethnic-specific carer support sectors or whether or not carer support centres can in fact develop the level of cultural competence to make it accessible to ethnic communities. I'm not quite sure whether you have a thought about that.

MR MIGLIORINO (FECCA): I can talk to it. Both in that discussion and in previous discussions, the missing element is an understanding of what is the service environment and the demography around that, so I could answer that in many different ways. I think what's really interesting - and I'll break up caring - in the first instance, caring or being a carer has become now an access code. If you identify yourself as a carer, you can get a carer pension, get carer support. In many ethnic communities, the word doesn't exist.

Now, what's interesting is that in the communities themselves - like, if I go back to Italy now, there is now a new word for "carer" which didn't exist in the lifespan of people who have moved here before. So the notion there is a very interesting one. When we start talking about "carer" and supporting it, two things need to happen: is there an appreciation in the individual carer that they are a carer and, secondly, that because of the nature and impact of language and culture and to some extent education level, caring is not one person but can actually be a collective. So in any family situation, you've got a personal carer, you might have an adult child who is the case manager, you might have someone else who's an advocate, and what the medical health system and the ageing system will need to cope with is when there's a decision needing to be made, then there is a whole troop of people.

MR FITZGERALD: Sure.

MR MIGLIORINO (FECCA): A lot of our medicos find that very, very challenging.

MR FITZGERALD: But in terms of public policy, as you say, just taking the issue of carer, in order to get the carer benefits, whether it's the pension or the allowance, yes, you've got to be principal carer, there's a whole lot of conditions, which in many senses, your communities would not meet because one of them isn't the principal carer, even if they wanted to access that. The question is: does the public policy simply acknowledge or does the public policy try to intervene in that in some way, shape or form?

If I can just be more specific: if the family in the community environment is in fact working well in order to support the older person, from a public policy point of view there's actually no issue. That's good; the family is working well, accepting the responsibility and that's fine, so there's no public policy issue at all. Where it becomes a public policy issue is where you've got the principal carer, they're not able to work, they're incurring hardships in a way - we recognise that as a society through pensions and allowances and now support services - so you're right, it's an access code. But from the commission's point of view, we don't think the government should be intervening unless - - -

MR MIGLIORINO (FECCA): It needs to.

MR FITZGERALD: - - - there's a demonstrable need or benefit.

MR MIGLIORINO (FECCA): It's really interesting because it goes into a lot of what the report talks about and that is the ability to afford care and what you can buy above and beyond a minimum standard. The two points I'd make to that is (1) the notion that they are fully functioning as units of care is quite often questionable.

MR FITZGERALD: Sure.

MR MIGLIORINO (FECCA): The reality is that there is a principal carer, and where I'm seeing a lot of it, it tends to be elderly women, that they're caring at their own cost. There is, for me, a knowledge gap there in terms of what is that health cost. There's some interesting stuff that came out of England two years ago, indicating that people caring for people in palliative care in home situations, that the carer's health decreased. What was interesting, even when that person being cared for went into residential care, their health continued to decrease. It was only when that person died that they started recovering. So my point is, yes, you can have situations where financially you can manage because a lot of the affluence in those families means that they don't want just the basic EACH or EACHD or CACP, they're happy to go and buy more. But the reality is that there might be people in that mix who are actually having to take the brunt of that and I think that's where the model breaks down. So in that care arrangement, we can actually have people being done harm through that care and we need to have instruments which are sensitive enough to be able to do that.

Now, the important point there, if they're seeing it as their duty, then the whole notion of actually going out and seeking support for that role becomes questionable. So it's at that point that the nature of or notion of carer needs to be part of an educative framework. So you do two things: (1) you educate that this is a code and cracking the code gives you all these other benefits but, secondly, the role of being carer in the society in which we live does not have to be that individual burden and can actually be shared. That's about education, in terms of what is allowable to be brought in.

MR FITZGERALD: I interrupted you. Are there other issues or points you want to raise that we haven't covered?

MR MIGLIORINO (FECCA): For me, there's a huge gap at the moment and that's research. I blame it on a number of things: the breakdown of the Bureau of Immigration population research which was defunded about 10 years ago; the very, very difficult role of getting research up, even in dementia grants. Right now, this field has absolutely very little evidence, and I'm concerned about that. In order even to answer some of the questions, what works or what doesn't work, do you actually look at multicultural models? Are they ethnic specific in localities? Do they go broader? My strong feeling, if we're going to drive public policy in this area, it has to be evidence driven and that is a huge gap at the moment. That was the only other point I wanted to make.

MR FITZGERALD: No, that's very good indeed.

MS MACRI: And there's a paucity of research generally, even outside of the

CALD.

MR MIGLIORINO (FECCA): And it's so important, even at the basis of demography.

MS MACRI: And it's the capacity and the ability to even attract research dollars.

MR MIGLIORINO (FECCA): Yes.

MS MACRI: We can recommend - - -

MR MIGLIORINO (FECCA): What's interesting also in this area is that there is some really good demographic data. What the ABS provides on a five-yearly basis is extraordinary. Our ability to be able to articulate language capacity, the level of education and length of time, and what we need to be able to do is to work back into the sector - at the moment we've got Departments of Health in every state who use this as absolute planning data but it doesn't migrate into the aged care sector.

MR FITZGERALD: Just on that research, there is a paucity of research, as Sue has indicated, in some aspects of aged care. I'm intrigued by the fact that we could probably say that there's not much research in relation to a whole range of areas relating to CALD communities and yet I would imagine that the university population which is the fundamental driver of research is itself very ethnically diverse now.

MR MIGLIORINO (FECCA): Absolutely.

MR FITZGERALD: So you'd expect to start to see some interest by some of those academics starting to flow through in the nature of the research. There's an issue about funding which I fully appreciate, but you would normally expect to see some sort of emergence in this area, but you're not seeing that. We're certainly not seeing it either.

MR MIGLIORINO (FECCA): No, the only significant pieces was funded by NHMRC which was to Prof Rowland on aspects of dementia on core communities. That's the only thing I've seen, whereas stuff done, seriously, in the 1980s and 90s trying to quantify the issues - Kate Barnett out of South Australia - again, most of it is 20 to 25 years old.

MR FITZGERALD: One of the good things with the gateway, if it can work effectively, is that it will become a great repository of information which we don't have at the moment and subject to the questions that are asked and the information gathered could be the basis of very substantial research. That's well beyond our scope. But certainly whilst gateways can have their problems, they also can be a very valuable in their collection of data which is not otherwise available or not otherwise released which, in the aged care area, is probably part of the greater problem. That's been really very helpful and I thank you for the submission and, as I say, with your members. That's been exceptionally helpful.

MR MIGLIORINO (FECCA):   Thank you.

MR FITZGERALD: If you have any other thoughts, please let us know.

MR MIGLIORINO (FECCA):   Certainly.

MR FITZGERALD: Thanks. That concludes our scheduled presentations. If there's anyone in the audience that would like to make a short statement on the record, they can do so. Yesterday we had four.

MS MACRI: None today.

MR FITZGERALD: None today, all right. Thank you very much. The public hearings stand adjourned until tomorrow morning when we resume in Brisbane at 9 am. Good, thank you.

MS MACRI: Thank you.

AT 3.54 PM THE INQUIRY WAS ADJOURNED UNTIL
THURSDAY, 7 APRIL 2011