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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Planning options and services for people ageing with a disability

FRIDAY, 18 FEBRUARY 2011

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SENATE COMMUNITY AFFAIRS
REFERENCES COMMITTEE
Friday, 18 February 2011

Members: Senator Siewert (Chair), Senator Moore (Deputy Chair) and Senators Adams, Boyce, Carol Brown and Coonan

Participating members: Senators Abetz, Back, Barnett, Bernardi, Bilyk, Birmingham, Mark Bishop, Boswell, Brandis, Bob Brown, Bushby, Cameron, Cash, Colbeck, Cormann, Crossin, Eggleston, Faulkner, Ferguson, Fielding, Fierravanti-Wells, Fifield, Fisher, Forshaw, Furner, Hanson-Young, Heffernan, Humphries, Hurley, Hutchins, Johnston, Joyce, Kroger, Ludlam, Ian Macdonald, McEwen, McGauran, Marshall, Mason, Milne, Minchin, Nash, O'Brien, Parry, Payne, Polley, Pratt, Ronaldson, Ryan, Scullion, Stephens, Sterle, Troeth, Trood, Williams, Wortley and Xenophon

Senators in attendance: Senators Boyce and Siewert

Terms of reference for the inquiry:

To inquire into and report on:

Access to options for and services to assist people with a disability and their carers to plan for the future, including:

(a) Inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers;

(b) Ways to ensure the continued quality of life for people with a disability as they and their carers age;

(c) The types of options and services that could be developed to help people with a disability and their carers to plan for the future; and

(d) Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?'.

WITNESSES

Subcommittee met at 9.02 am

ROSIE, Ms Linda, Manager, Carer Engagement Project, Mental Health Council of Australia

TATZ, Mr Simon, Director of Communications and Marketing, Mental Health Council of Australia

CHAIR (Senator Siewert)—Welcome to the hearing. Information on parliament privilege and the protection of witnesses has been provided to you. If you need a reminder—I know that you, Mr Tatz, have been here before us on many occasions, but I am not sure if Ms Rosie has—we can help you with that. Would you like to make an opening statement?

Mr Tatz—If it is all right, we have not got a written submission. We would just like to make a brief presentation and then answer your questions. The Mental Health Council of Australia is the peak national non-government organisation. We represent and promote the interests of the mental health sector, particularly mental health consumers and carers.

As background to Linda Rosie's presentation, in 2008 and 2009 the Mental Health Council of Australia, through funding from FaHCSIA, conducted 116 workshops with mental health carers across Australia. This was designed so that we could have the first ever national survey of the experience of mental health carers. Over 1,500 carers attended these workshops and two-thirds of them were held in rural and remote locations. While mental health carers are more often older people, the workshop specifically engaged with young carers, some as young as nine years old.

From these 116 workshops, the council gained invaluable data and insight into the lives and experiences of mental health carers. From that, we produced a landmark report, which I would like to leave with the committee, *Adversity to advocacy*. It gave unique insight and was the first report ever into mental health carers in Australia, and it was launched at Parliament House in Canberra. From these workshops, 15 major issues were identified and we presented that as a report card to the government. I would also like to leave that with the committee. In November 2010 we launched follow-up document called the *Mental health carers report 2010*, which again I would like to leave here. What this did was collect data a year a later to see what had changed with mental health carers and to try to provide an annual snapshot and updates on mental health carers. This was the first quantifiable measure of the issues facing mental health carers in Australia. So we have published two landmark evidence based reports with the most current research into carers. We hope through continued FaHCSIA funding we can continue to produce reports annually, and it is on these reports that Linda would like to give a small presentation.

Ms Rosie—As well as the reports that Simon mentioned, we also host a mental health carers internet forum, and some of the comments that are coming today will have come through that forum. This is very current. It is happening as we speak. The comments by carers who care for someone with a mental illness at home are quite profound. One of their major concerns and one of the reasons we are here today was item (d) on your terms of reference: what happens when I am gone? We heard that again and again at the workshops and it is something that continues. Mental health carers do not know what is going to happen when they die. They are concerned about the lack of options and the desire is that family members do not have to care for a sibling when the parents are gone. These are major concerns.

We had 765 responses to the carers report 2010, and I will give you a little bit of background of who these people were. They were all mental health carers. Eighty-two per cent of them were women, 60 per cent of them cared for an adult son or daughter and the average age of the carers was 58—that is the average. Thirty per cent of the carers were actually over the retirement age of 65, and 88 per cent of them were over the age of 45. We are talking about seriously ageing people. Sixty-one per cent of them said that the consumers had lived with them during the last 12 months. So we have a picture here of adult sons and daughters living at home with ageing parents or carers or a single carer. One of the most staggering figures was that 77 per cent of the respondents said that they were responsible for the day-to-day integration of any sorts of support systems for the person they cared for, whether they lived at home or lived out of home—not social services, not PHaMs workers but the carers themselves. And they were very willing to do this.

So we looked at the question: why do so many consumers live at home? They are not able to live independently. These mental health consumers are not able to live independently and there are no other options available to them for their accommodation and care needs, and there is supported recovery based care that they need when they are living independently. We asked carers what sorts of things they would like to see in accommodation options for the consumers. They said they wanted local, available, long-term options—that is very important, so that they provide a home for the consumer. They also wanted appropriate—that means supported—resources and choice of accommodation. Many mental health consumers do not want to live in a group home.

The MHCA looked at the current options, and there is no service that we could find on a national basis that is devoted to the needs of mental health consumers who live at home with a caring family as they age. There are some excellent examples around. The HASI program, which is the Housing and Accommodation Support Initiative, started in New South Wales about 10 years ago. That has been well documented and well evaluated. Its fundamental basis is like a milking stool: it is three pronged. It works as a partnership with housing, mental health services and non-government organisations. They work together in partnership to provide the sort of accommodation that mental health carers talk about—that long-term supported accommodation.

CHAIR—Where was that one based?

Ms Rosie—That started in New South Wales—it has spread. The problem is that it was started from a homelessness perspective—and very rightly so; there are many people with mental illness out on the streets—so the priority for the housing program, and I got this information yesterday which means that it is very current, is that accommodation for mental health consumers is provided if they are in hospital due to their high support needs, if they are homeless, if they are at risk of homelessness, if they live in inappropriate housing or if they find it difficult to maintain stable tenancies without high level support. Given the undersupply of housing accommodation, it would be very difficult for consumers living in the safety of a loving parental home to meet these criteria.

Housing is the best known and best evaluated option, but there are other ones around. Within the evaluation in 2010 of the housing system, it was found that they were meeting their goals with some of their target groups, but, when it came to CALD carers, they were not meeting their targets. So that is one of the groups that are identified as really in need. There is an independent living program in Western Australia that is on the same basis as the housing program, and there is another one. This one really tweaked my interest.

Senator BOYCE—What is the name of the independent living program in Western Australia?

Ms Rosie—That is what it is called. It is very similar to HASI.

CHAIR—In other words, the priorities are the same. We will ask a lot more questions later, but these are just for us to clarify stuff first.

Ms Rosie—It is on basically the same basis: it provides high-level and low-level support, it has the accommodation options and it has the working in partnership, which is the important bit. There is also the HASP program—Housing and Accommodation Support Partnerships—which started in Queensland, I think, and it is just being rolled out in South Australia. Again, it is similar to the HASI. This is very interesting, because within its statement it does provide an example of people at risk of becoming homeless: those living with elderly carers who are unable to continue caring for their family member. Within its statements it does actually see the need there, so we are very pleased about that. However, there are only 84 places coming on stream, and if you look at the population of Adelaide, which is about 1.3 million, and look at a population of, say, one per cent of people—which is a low estimate; that is the generally accepted estimate of people with schizophrenia in society—who would need this accommodation, then a conservative estimate would say that we would need 13,000 housing units for those people. So 85 places are very welcome, but it really is a drop in the ocean.

Also, the HASP program in South Australia is in the metro area only, so if you are in rural and remote South Australia your options are very few and far between, and this applies to the rest of Australia too. If you are in rural and remote Australia, both your recovery based care options and your accommodation options are seriously limited. There is another option that mental health carers have looked at—and I stress that it is mental health carers we are talking about—which are parents who put themselves in a position to provide accommodation for the person they care for. People we know have accessed their super and bought a unit for the person to live in or sold the family home and bought two units—one for themselves and one for the carer—and these carers have raised the problem with us of being penalised for doing this. So we looked into this issue, and I have an example here which reads, ‘Carers reported selling their family home and purchasing two units: one for themselves and one for the consumer. The carers were then denied benefits because of the gifting rules at Centrelink.’ Gifting rules basically say, ‘$30,000 and that’s it.’ So we looked a bit further: we phoned Centrelink. They said, ‘We have a special disability trust which covers all this.’

Senator BOYCE—We know all about special disability trusts!

Ms Rosie—So we looked into this. However, this is another situation where mental health carers slipped through the gaps. This is not available to them for a couple of reasons. If we go back a bit and talk about carer payment and carer allowances also provided by Centrelink, they have recently changed their forms. These forms are hard to access. You cannot get them on the internet; you have to go into Centrelink offices and ask them to print them off for you, which we did.

CHAIR—We have them coming in.

Senator BOYCE—That is an estimates question.

CHAIR—We did not think to bring Centrelink in today. We have FaHCSIA and DOHA. We will follow it up at estimates.

Ms Rosie—Basically, the forms are still designed in a way that is supportive of people with a physical disability or mental impairment. When you are talking about mental health carers, the forms are not designed for that. They do not cover what mental health carers do. That is one problem. The other problem is that, in the latest forms I have seen, mental health carers do not give much information about what they do, so it is left up to the treating physician or the medical person to provide that information. Given privacy and confidentiality around consumer rights, the carers often do not have access to the GP. So here is a carer going in cold to a GP they do not know to ask them to fill in a form about one of their patients. It is fraught with problems for the carer. Often mental health carers are still being denied carer payment and benefit. That is important. We looked into this a bit more. There is something called a disallowable instrument, which is based on the Adult Disability Assessment Tool. This defines how the forms should be constructed. The ADAT is defined as part of social security law. In a phone call to Centrelink, they said that they could not to change the forms unless the ADAT is changed. So it looks as though it needs some sort of change in legislation—but I am no lawyer—to change those forms.

I go back to the special disability trusts. You can put $500,000 into a trust for the benefit of the consumer—that is the basis of it—which is great. That could buy a unit—maybe not in Sydney. Compliance for the ageing mental health carers, where the consumer lives at home, is very difficult. These are the actual stated rules on the internet: the consumer ‘who has a disability that would, if the person had a sole carer, qualify the carer for Carer Payment or Carer Allowance’. That is one of the criteria where the mental health carers fall down. Another one is: a consumer who ‘is living in an institution, hostel or group home in which care is provided for people with disabilities, and for which funding is provided under an agreement between the Commonwealth and states and territories.’ The consumers we are talking about—that is, 61 per cent—are living at home with their carers. They are not living in an institution or a group home. So disability trusts—as far as a MHCA would read this—are unavailable to mental health carers who have consumers living at home.

CHAIR—We will go through the rest of the criteria, but I know people who are trying to access special disability trusts. A lot of them are still living at home. This is not just about mental health consumers; it is about people who qualify more under the current rules. There are a lot of people who are looking at this option whose children are living at home.

Ms Rosie—If you have a disability and a mental illness is co-morbid with it, then that could qualify you, if you had access to the carer payment, but, as far as our reading goes—and all we can find out is what is published on the internet—the second criterion, about the consumer living in an institution, hostel or group home, would really limit ageing mental health carers with a consumer living at home. That is all we can find out.

In 2006, consultants employed by FaHCSIA conducted research around Australia into succession planning for carers. That report is available on the internet. It was published in 2007 and it seems as though the situation has changed little for carers in the last four years. With regard to special disability trusts, that document says:

> The definition of severe disability is considered too limiting, and many people with mental illness and other disabilities would not meet the criteria.

That is from the 2007 FaHCSIA report.

CHAIR—That has changed.

Ms Rosie—Has it?

CHAIR—You will be aware that we conducted an inquiry into special disability trusts a couple of years ago. There have been some changes made already and there are further changes in the legislation currently before parliament. Again, it does not address all the issues here but they have loosened up the issues around the definition of disability.

Ms Rosie—Great.

CHAIR—But I think the other issues you have mentioned are still to be resolved.

Ms Rosie—Yes. We have not brought a carer with us today but I do have a current story given to me on the Carer Forum on the internet quite recently. It is a mother called ‘M’ and this was posted about six months ago. The conversation about accommodation and what is going to happen when we die is one of the matters that is regularly visited by the mental health carers. Six months ago she posted this good news story:

‘My son had been in long-term institutional care for seven years’—so he was accessible—‘and before that lived at home with us for six years from the time of his initial diagnosis of schizophrenia. My son is loving having his own flat and personal space after so long in institutional care. The Housing Commission flat he is in is a very comfortable two-bedroom flat and pretty new. It is only a 10-minute walk from town and is on a bus route, which is excellent as he is unable to drive. He is enjoying the freedom. His self-steem has improved and he enjoys grocery shopping and looking after himself.’

‘My son’s HASP package is indefinite. He has signed a 10-year lease on his Housing Commission flat; his support workers call in every morning at 8.30 to wake him up in order to ensure that he has his morning medication. He is good at taking his evening medication and needs no reminder for that. Every weekday afternoon one of his support workers will go to my son’s flat and either help him with his housework, take him grocery shopping or take him on an outing. He has been assigned 20 hours of support workers a week, so that is four hours a day Monday to Friday inclusive. He has started having his father and I over for dinner on Friday evenings and is cooking quite reasonable meals for us. We collect him on Saturday morning and he stays with us until Monday when his support worker collects him and takes him to a social group held for young people with mental health problems. He really enjoys the support group. So I emailed him and asked could I have permission to read this to you which he willingly gave.’ But she said ‘I’ve got an update’. This is the email I got two days ago from her–six months later:

‘The accommodation was okay. It was a place to go when we were in great need. We were both appreciative to have an option at the time and in my mind it is located in a safe and fairly upmarket area of the city. For the type of place I could not ask for better in terms of safety of location and proximity to the CBD. My son initially saw this as a first step into freedom and a place of his own but ultimately, as he became more well, he found the environment less attractive due to the lack of privacy, theft of his belongings and at times having to deal with unpleasant and threatening residents. The owner is a very approachable person but the bottom line was that there are all sorts of residents there with all manner of problems. Some have been in gaol, some are alcoholics, drug addicts et cetera.’

‘What was taken care of were meals, medications picked up each week and dispensed, linens changed regularly, rooms cleaned and there was a manager from 7 am to 7 pm with a night caretaker—all most appreciated. So there was some relief for me as a full-time carer in terms of daily stress and, after an initial period of concern regarding issues of safety, one simply came to accept the bad with the good. What was missing, however, was any form of rehabilitation. The public case manager did not eventuate. He stated that due to our affiliations with a private doctor, he would not become involved with my son. It should not have come down to a battle to get some case management. As a single parent I chose to pay for private health insurance for my son and as a taxpayer the one time I have asked for something from the public health system I found that request denied. Once I learned the case manager was not going to eventuate I found a community welfare organisation myself and asked them to visit my son–which they did regularly. What is needed is a support person who can guide consumers and carers through the myriad of programs that could be helpful in rehabilitating and restoring or maintaining wellbeing—a gatekeeper of sorts. The doctor does that with medication, but my son was left at this supported accommodation place without a gatekeeper for rehabilitation. My son would dearly love to live in his own place. He has applied for an apartment and that wait list is apparently around five years or so.’

Remember he is living at home now with his mum, so it might be even longer. She continued:

‘And now with more and more homeless following the floods, that wait could be longer. So in my humble opinion there is a huge need for supported accommodation that provides shelter, safety, basic living and some rehabilitation options and there needs to be someone looking out for the welfare of those vulnerable folk who do not have the skills necessary to protect themselves from the wolves that are around.’

She gives a very clear indication of what she sees as lacking in supported accommodation. Certainly we have the PHaMs workers, who are fairly new online and they could fill that gap. The ones we know of do an excellent job but they are not widely available, particularly CALD groups in rural and remote Australia. We do know of individual mental health carers and consumers who have done fantastic things out in the rural community. We know of a group in Gunnedah who were not initially supported by mental health services and who voluntarily set up a rehab day program for mental health consumers. The organiser of that has just recently been awarded citizen of the year. These groups are loosely affiliated with the national volunteer organisations, but I am not sure of which ones. There is another group in Hervey Bay where one person has actually organised the council to provide accommodation where she supports mental health consumers in living independently.

So there are little pockets of people doing this completely voluntarily because they see the need. But in rural and remote Australia such help is even less available than in the cities. I think one of the problems is that mental health really came late into the disability camp. It is not well catered for in the provision of statements or documents that were made a long time ago. Mental health is still on the outer fringes and it is not totally in that camp yet and that is where a lot of the problems are for the carers that we have talked about today. They have poor access to a limited supply of accommodation on offer. They also have little recourse to the special disability trust. At the moment they are penalised for their generosity in providing independent living for the person they cannot care for. We have heard of mental health carers who have had a bar of five years placed upon them by Centrelink for receiving the aged care pension because they have bought a unit for their son or daughter to live in.

CHAIR—The carers have?

Ms Rosie—The carers have bought the unit for the consumer to live in.

Senator BOYCE—So that because of what is perceived to be their gifting they miss out on the pension for five years?

Ms Rosie—Yes, on their inability to access this special disability trust. The other thing is that many mental health carers just do not know that it exists. If they cannot access the carer payment and benefits, it is not the money but the need to be able to access it so they can get on the list.

CHAIR—I am conscious of time. Have you finished your presentation? We have been questioning you as we go along, so we have already started the questioning process but it would be good if we move formally into questions.

Ms Rosie—Yes.

Senator BOYCE—You talked about the Independent Living Program in WA and HASP in New South Wales. As far as I can see, the core of this is not actually the provision of services, it is the safeguarding around the quality of the services, appropriate services and so forth. How do these groups go about doing that? What distinguishes them from any good supported accommodation?

Ms Rosie—The point is they have this partnership. They have a partnership between housing, mental health services and the NGO sector, so housing provides the accommodation. This is my understanding and I am not an expert on housing. The mental health services provide the services that are needed—if people need to have injections, medication and that sort of thing—and the NGO sector provides the recovery based options for the consumer, such as the day-to-day visits, the taking out, meeting other people, helping with cleaning and those sorts of things. And often the workers who are involved in that are personal helpers and mentors which is a fairly new initiative into Australia and one that is well approved of and thought of great value by the carers who are able to access that for the consumers.

Senator BOYCE—Are they the people you would see as providing the ongoing quality control, for want of a better word, when the carers cannot?

Ms Rosie—Yes. I think the point that ‘M’ made in her story is that the success of this process depends on having a key person rather than if it is just a series of different people going in and helping with shopping and with all of the essential needs—which is often what the carers do—and if you do not incorporate that recovery based involvement with groups, such as going to art classes or whatever it might be, with the gatekeeper for that one person taking responsibility. ‘M’ highlighted that quite significantly in the failure of the supported accommodation for her son. That seems to be integral and core to the success of this process.

CHAIR—We have had evidence around microboards because the issue that is coming up time and again is who is going to look after my son or daughter after I am gone. One of the concepts, and it does come out of WA as well although I know they are considering it elsewhere, is that of microboards where you establish one, two or three people who take on responsibility for doing just what you said in terms of making those overall coordination decisions, and in some cases helping with finances or taking responsibility for financing and then coordinating services and things. Have you any experience in that area?

Ms Rosie—I do not, I am afraid. But I can see that while family members often would be willing to take on partial responsibility for their siblings, and often want to, there are some people who should not be expected to take on that responsibility. I can see that that would work very well if the consumer is in there as part of it, because it is their life and they need to make those decisions around what they want to do. I could well see that that would be very supportive and certainly would look at the best interests of the consumer as to what was appropriate.

Senator BOYCE—I know there have been some moves by parent groups, for instance, to buy blocks of flats and have someone, a manager, live in the block and things like that. Some of the attempts by parents to informally look after what is going to happen when they are not around bumps up against de-institutionalisation policies as well. Could you give us some of your experiences there and what the council’s view is on that topic?

Mr Tatz—Some of the states like WA have specific housing for people with multiple sclerosis that are grouped where a person with MS and their family are accommodated in specifically designed accommodation. There are acquired brain injury units along that line. I think the main point would be about the linkages they have with other parts of both rehabilitation and services and also the options that are available for the consumer and for the carer for when they are no longer around. We talked about the choice that consumers would have. In the old-style meaning of the word ‘asylum’ or sanctuary, it is to have a place where people are looked after but are given choice and options in a safe environment where family support and the gatekeeper type person is able to help manage a range of things. As we know, the word ‘asylum’ has a lot of connotations, but the original concept is meant of having people looked after safely but given options and choice. I think the thing that Linda and the council really want to emphasise is that the consumer needs to be able to actually have input and a role to play in this as well as, obviously, their carers. If the model you were talking about can be adapted to provide that it is definitely something worth looking at.

Senator BOYCE—I just find that I have some concerns about it in that I am not sure when a block of units turns into a institution, given that some of the people living there are not always going to be cooperative about their care.

Mr Tatz—I think, as Linda highlighted with the experience of ‘M’, is that what starts out well—‘we’ve got somewhere to live and it seems good’—can turn into something where the options and the choice are limited. As the person gets well they find they do not have the help, rehabilitation and support that they need. I think the key in constructing a system is that we do not end up, as we did with asylums, where they became worse for people’s mental health and obviously for carers.

CHAIR—The other issue there is when people become more unwell because mental illness is often of an episodic nature. We have dealt with that quite a lot in our inquiry into suicide. It came up there that when people get ill the support services are not there and they lose their accommodation in terms of not paying bills, all sorts of things.

Ms Rosie—And that is very much a part of mental illness—the inability to pay the bills, the inability to find the bills. As people become unwell the general skills that are in place, as we normally accept in daily living, just disappear and so they lose accommodation. They cannot get it again, and they disappear. All sorts of problems emerge from the nature of mental illness that are not really the case in other disability areas.

Mr Tatz—One of the things that came up when Linda did the workshops and we travelled around Australia is that a lot of carers were not looking for respite particularly in ethnic and other communities where it is the appropriateness of that but also what happens when people were in the community; if they have an episode, they lose their housing. We have documented that quite well; the issues around the lack of support for people who experience difficulties and are then evicted, complaints by neighbours or others. That is why I believe so many consumers still live at home because that provides that continuity. But an issue we found was about choice and support and services coming in. Not everyone did, but quite a number of carers said it was not respite particularly that was helpful but appropriate respite, culturally aware help and support as they got older.

Ms Rosie—I think one carer put it beautifully about accommodation when she said that if you try and find just rented accommodation for your person—and we are talking about adults of say 40 years of age, who want to live independently, they do not want to live with their parents—that even in private rented accommodation it is very hard to get decent accommodation if you are on a disability support pension and if you compound that with mental illness landlords just do not want to know. So they are on the backburner in every way.

CHAIR—And this comes back again to having a good support coordinator. I am just trying to work out what recommendations we could be making to government, to say that these are the things you could do to fix these issues because on top of all the other issues to do with planning for ageing with a disability, mental health needs some additional recommendations. That is the way I am seeing it at the moment in terms of dealing with the episodic nature of illness—when people are well, when people are not, the issues that you have just raised. So the key things that you would suggest that we would recommend would be: coordination and support, and case management seems to me one of the key things you are talking about as well.

Ms Rosie—I think it is, but I think if we get back to the hierarchy of needs the first thing you need is a roof over your head.

CHAIR—Sorry, I take it as a given that what we have to do is make sure we have got accommodation. A common thread across all of the evidence that we have heard is the issue around accommodation. So I am then looking at the situation where just finding accommodation does not do it. You have then got to make sure it is long term.

Ms Rosie—We have a workforce issue when we get into the areas of the support systems needed for people who have a mental illness and are living independently. We do not have a career structure in that area. We have got qualifications at TAFE now, certificate IVs, but we do not have the trained staff and often people will leave, they will leach. They get the experience, they learn how to do things and they move on to another area that is better paid. When you come to the mining areas in rural and remote Australia, people just go and drive a truck in the mines because it pays them twice as much—and rightly so, they can be single parents and they have got to do this. So the workforce is another issue. The institution of the personal helpers and mentors, the PHaMs workers, was a great step forward. A lot of those are carers themselves because they know the need, they have got the experience and they really want to help in this area. We have little structures in place that could be built and worked upon and become quite comprehensive. They could provide the sort of integrated networking and the partnerships that we need so that people get that care. The coordination of services is another big problem when people are actually accessing services. There are quite a few bits of services all over the place, but knowing they are there and how we coordinate them is another issue altogether.

Mr Tatz—Just to reinforce Linda's point, almost everything the Mental Health Council does in every presentation report tends to come back to workforce—that we do not have a sustainable workforce, that people leave. The mental health of carers, mental health nurses and professionals is another issue. So we lose continuity of care. Again to reinforce Linda's point, we have seen models—I think they have one in New York State with their pathways program—that are a kind of PHaMs or caseworker management in housing and accommodation so there is someone there. I think in New York State—I do not know if it still exists—the state was the renter and they would rent the property like public housing, but they would be the guarantor and put up the bond. So for a person with a mental illness who is on a support pension and who cannot afford to get into the housing market or maintain it, the state played a role in ensuring things like bond, helping maintain if there were problems with the rent, and perhaps case managing if that person went to hospital for a week or two and bills were not paid. That continuity and linkage is very much linked to workforce where we just have no continuity of care, as you would know, across all the areas of mental health and disability.

Ms Rosie—In the UK they have something called support, time and recovery workers. I heard about these about six years ago. I do not know a lot about it, but I do know that there is integrated within this workforce a career structure. I think that is one of the things we seriously lack in the mental health area. We have wonderful workers on the ground with mental health consumers, but they leave and we lose them. We would like to retain them.

Senator BOYCE—We are expecting the Productivity Commission to fix the workforce, the housing and the services issues. And we were seeing this as complementary in the sense of concentrating that point that you can have great housing, you can have great services, but if there is not someone there to care you can very easily fall through the cracks if something goes wrong. One thing that has been suggested to me in the past is that because of the episodic nature of many mental health problems, parents and carers in this particular area are less likely to plan for the future and may in fact feel that they are underestimating or letting down their child with a mental health problem because they feel that they are saying ‘Well, you will never get better by doing work’. Can you talk a little bit about whether that is the case and how you might approach planning for people like that?

Ms Rosie—I think that is very true and that comes through in the 2007 report as one of the comments of carers. There is always the hope that people will get better. We need to have hope. I think that probably is a problem. I do not know enough about it, but I should imagine that mental health carers would find it a problem in terms of planning for the future because you hope that they will get better. Also they have the knowledge that there is very little that they can actually do because there are very few services out there. It is very hard to look to the future. They just worry about it, because they do not know how to plan when there is nothing there that they can plan with.

Mr Tatz—There is also the other element that we came across in Linda’s research of young carers who are caring for their parents. This is often forgotten. We heard stories of ‘I can’t go to university’, or ‘I can’t pursue my career because I am the one looking after a parent with a mental illness or who needs ongoing care’, and that is a rather tragic part. I think Linda said the youngest carer was nine years old.

Senator BOYCE—It sets them up for a lifetime of poverty.

Mr Tatz—Young people being trapped not knowing and not planning for their life. We came across a brother and sister who had no life. They cared for a mother who required 24-hour care and it was a great sadness. They wanted to go to university and they wanted to perhaps marry and have a life but felt trapped because they were the carers. So there is that element that does not always get considered—the one of young carers.

CHAIR—When you miss out significantly on schooling as well.

Ms Rosie—With mental health in the family, and if there is drug and alcohol there—we know drugs and alcohol and mental health often go together—they are not going to identify as young carers. With other young carers it is quite obvious there is disability in the family, but mental health carers will shy away, and their parents will do exactly the same, because they have a great fear of their children being taken away from them. I personally know of a young carer who was caring at the age of five and six—locking up the doors at night, turning off the TV, making sure his mum was okay. He is not documented but that is what happens because there is no one else. It is very sad.

Senator BOYCE—In terms of disability at the present time, it has been brought to our attention that if you want to move interstate and you are the person with the disability, there is no guarantee of any services from one state to the other. You end up with families split up because you do not want to run the risk that they will not get funding when they move into the other state. Have you had any experiences with that in the mental health sector?

Ms Rosie—In the mental health sector I can say that cross-border issues in terms of compliance for medication is another major issue. It is one of the problems with mental illness that if people have a mental illness they will often go walkabout. We are talking serious mental illness here. We had a case a few years ago—Simon is good at remembering names—when a German woman—

Mr Tatz—Cornelia Rau.

Ms Rosie—That is not untypical. The family is left isolated within a state where they do not know where the person is, they are not getting service, they are certainly not getting medication. When it comes down to the core of getting medication if people move states the services are not integrated such that they can provide that knowledge to service providers in other states. Privacy and confidentiality comes in here as well. The coordination of services on a state level as well needs to be looked at so that we can actually provide that safe, harmonious way of moving.

Mr Tatz—We have come across this in disabilities and mental health where it is more than common for the mother to be left, for the marriage to break up and we find a single parent as the carer both with disability and with mental health. The situation is often more complicated. I think the divorce or separation rates in these families is extremely high. In some areas I have come across in disabilities where 90 per cent of the carers were single mothers. We have the factor that the carer may also be on their own or without the support that they need. Obviously then the financial aspect of being a single person as the full-time carer, even if it is official or unofficial, creates myriad problems in terms of just ongoing care.

CHAIR—I want to ask about planning and my question comes back to the specific nature of mental illness and the episodic nature of mental illness, which is an issue that has also come up in another inquiry. It goes both ways: if someone gets well they do not want their family involved and if someone becomes ill they do not necessarily want the family to be involved. So there is this big issue about how carers then can plan for the future where the person does not want them to be planning. For our other inquiry that was certainly a big issue. In terms of long-term planning how do you build that in?

Ms Rosie—I think that you have raised a major problem that incorporates privacy as well. When the consumer is stable, they value and appreciate the supports they get from the carer. When the consumer becomes unwell one of the things that often happens—and it is very bad for the carers—is that they will end up in a psychiatric ward and the last person they want involved is a carer because they have ‘caused all the problems’. These people are seriously unwell but that is what is accepted by the medical staff so the carers are excluded at that point. So that is the acute end of things. When it comes to long-term planning it is very difficult. I am sure there are ways around it, but the problem you have highlighted is one that I would expect has existed—I cannot say I have any knowledge or evidence of that. And I take us back to that 2007 report which talks quite a bit about these sorts of issues—the difficulty of the long-term planning, the not wanting to relinquish hope and the inability to plan when someone has a mental illness, is often unwell or on the verge of unwellness. Then when is the consumer actually stating what they really want and can someone else speak for them and should they? It is a very difficult area. Just the idea of what you mentioned about three people looking out for the interests of a consumer, with the consumer involved. If they know that consumer well and they are there on a long-term basis that would seem a very good support for mental health consumers who are willing to accept that.

Mr Tatz—If I could add that when workshops were conducted the issue of privacy was a big point. In answer to your question, I would say the issue is the involvement of carers in the care process. We heard terrible stories of one example of parents whose child had episodic mental health and attempted suicide. They took their child to the emergency department and they were literally stopped—I think we gave this evidence at the suicide inquiry—

CHAIR—Yes, you did. We also had a carer presenting evidence.

Mr Tatz—And then they are there to pick up the pieces. So the lack of carers involvement in the medical model and the medication is, I believe, one of the things that inhibits the ability of the carer to plan.

Senator BOYCE—They might even not know what the medication is sometimes.

Mr Tatz—Just as a quick aside, one of the things that came up also in the workshops was the lack of knowledge being provided to carers about changes in medication. As the medication changes, so does the consumer’s behaviour. Carers are not given this information or supported in this. I believe that if we are going to improve the long-term planning there has to be a better process of involving the carers in the medical treatment of the consumer and not shutting them out through privacy laws.

Ms Rosie—We asked these questions in the 2010 report to try to get at this sort of information and many carers said that things had improved with their GPs. That could be because some dementia and Alzheimer’s people have answered this report. We will try and weed that out in the next report—if we get funded. We then asked the question: did they feel they were part of the care team? And I have not got the figures to hand, but a very large proportion of carers said no, partially, sometimes, occasionally—those sorts of things. But what we need is that the carer is a recognised part of the care team.

CHAIR—We have run over time—it is my fault. As you can tell, we could keep talking about this for a very long time. You have tabled those reports, thank you. And thank you very much for your time; it is very much appreciated.

[9.54 am]

AH TONG-PEREIRA, Mr Brandon, Policy Officer, Vision Australia

CHAIR—Can I please welcome Vision Australia. I understand the information on parliamentary privilege and the protection of witnesses has been provided to you.

Mr Ah Tong-Pereira—Yes.

CHAIR—We have your submission. I would like to invite you to make an opening statement, and then we will ask you some questions.

Mr Ah Tong-Pereira—Thank you for this opportunity to come before you today. We at Vision Australia believe that a mark of a great nation can be measured by the way in which we show gratitude and respect to those who have worked, guided and nurtured the lineage of those who are coming after us in the future, those who have carried us into the present and set the platform for the future, those who continue to be full members of our social, economic and cultural fabric and who live into their senior years. We believe this regardless of the contribution that they may have made during their earlier years and whether they be captains of industry, public leaders, mothers, fathers, those who give comfort to others, those who remind us of the diversity of our shared humanity and, in this age of global interconnectedness, regardless of their time in this country. People who are blind, people who are deafblind, people who have low vision and people with disability more generally are part of every walk of life and show all manner of our diversity. They are part of our humanity, not apart from it.

It is with these beliefs that we applaud the work being done by the committee into the planning options and services that are available and what is needed now and into the future for people who are ageing with a disability. Within our comments and fourteen recommendations provided to the committee in our written submission, we have outlined the concerns for the work being done here, mindful of the work being done in other places—not least, the work being done by the Productivity Commission into a lifetime care and support scheme and other work in aged care and also the work being done at the state and territory levels around similar areas—because we believe that this combined work will help guide us in our work not only in the services themselves but also in how we can plan for services for people ageing with a disability.

What we do at Vision Australia can broadly be seen as skills development for independent living, information access, peer support and advocacy to remove those barriers so that disabled people who are blind or have low vision can live the life of their choosing in our community. What that basically means is that we are about assisting people with skills development, learning how to read and write using other methods such as the little Braille note I have in front of me today. So there are ways of reading and writing as others have done before or, if they are blind or have low vision from early in life, continuing on to do that in their later years. It is about tapping into the things that enable you to continue your mobility in our community—learning to use a white cane, using a seeing eye dog or the like. And there are other incidental things such as using other devices or learning better and safer ways of going about duties around your house, making breakfast, dinner, teas and coffees. Then there are the things about peer support so people still engage in the recreational and leisure activities that you and I and everyone else enjoy.

Skills development is about trying to enable people to live the life of their choosing. That is regardless of age, sex or any other delineation of a demographic. Peer support is really important. It is about being around others who may be in the same situation as you, learning from them, talking to them, sharing your experiences and leaning different ways of doing things you may not have heard of before. Advocacy is about breaking down the barriers that people face. We believe that disability is about people with impairments interacting with the environment and social attitudes. Advocacy is about ensuring that people, having learnt skills, having learnt different ways of doing things, having learnt about the options available to them, are actually able to use all those in the community.

Thus it should be said, as we mentioned in our written submission, that aside from the incidental guidance that we support we do not generally provide services around planning for the future. We noted in our submission that we have one particular area, the community aged-care packages program, where we have case managers who provide a range of supports for frail aged people with disabilities. Most are clients of Vision Australia with blindness or low vision. Part of that component is a planning and assessment cycle. However, that is directly related to an individual’s package and not a general service that we provide. We currently have about 60 clients who come into that category out of almost 46,000 clients we have across the country. We provide services in Victoria, New South Wales, ACT, Queensland and we also provide library and information services to every state and territory. We also have seeing eye dogs in every state and territory. Our key points of information access and specialised services are about enabling individuals to be informed of the options available to them later in life and ensuring they have access to the services that are needed by people who have blindness or low vision. I would be pleased to elaborate on these in more detail with you this morning and again thank you for this opportunity.

Senator BOYCE—One of the core reasons that we are holding this inquiry is to look at that question of the concerns that parents have about what will happen to their vulnerable child, irrespective of whether that child is young or old, when they are no longer around to care—that they are getting the right services, that they are being delivered well. Could you tell me a little bit about what the level of concern in this area might be within the vision impaired community. I imagine it is quite different from the area of cognitive disability.

Mr Ah Tong-Pereira—I would like to clarify this. Are you talking about parents being concerned about the children?

Senator BOYCE—In the intellectual and physical disability field you have parents in their 80s caring for people with disabilities in their 50s and 60s and not knowing what is going to happen when the parent cannot care anymore. Is this an issue in the vision impaired community and if so, to what extent?

Mr Ah Tong-Pereira—An interesting question. From my understanding in terms of blindness and low vision it is not necessarily an issue as with other disability groups. Vision loss in itself, or blindness in itself, does not necessarily mean that an individual requires care.

Senator BOYCE—Or is vulnerable?

Mr Ah Tong-Pereira—Or is vulnerable. Most people live independently whether they are born blind or have low vision, or develop blindness or low vision like most people, later on in life. As I mentioned before, the skills that we provide through our services help people to actually continue to live independently. Independently means that if you lost your vision later in life you can do things that you may have done in the past —reading, writing, working, going to school, education; those sorts of things. Independently may also mean having assistance to do things. Maybe it is about having a reader come around once a week. To come back to your question, I do not suspect that that particular issue is an issue faced within the blindness and low vision community. There will be exceptions, of course, but generally speaking it is not necessarily a large concern.

Senator BOYCE—You have raised the issue of accessibility of information. Can we split that up into two sections, firstly, the ability to access existing information: how good or bad is that? Secondly, in relation to information out there, we have had witness after witness saying that it is impossible for anyone to get their head around all the stuff that is available and to understand what is truly available.

Mr Ah Tong-Pereira—Yes. That delineation of information is a good one. Let me start by saying that information access itself is about having access to all the information that is available at the moment. What this means is that currently there is roughly only about three to five per cent of all published information available to people who are blind or who have low vision.

Senator BOYCE—Three to five per cent?

Mr Ah Tong-Pereira—Three to five per cent, which is 95 to 97 per cent of information not available.

Senator BOYCE—That is all information, not just government information?

Mr Ah Tong-Pereira—That is published information. Information is a very broad area. Signs are information; timetables are information. That figure comes from a study that is done in the UK that we cite in lieu of any other similar study here.

Senator BOYCE—That is extraordinary.

Mr Ah Tong-Pereira—Definitely extraordinary. I would actually go so far as to say that figure is much worse than that, if you consider all the information available. The world wide web is a great tool and people who are blind or have low vision who use adaptive technologies find the world wide web a great source of information. It is also a new source of a barrier that was not existing before. To come back to your question, on the information available right now, there is an issue of having it available in a form that people who are blind or have low vision can access. I can load documents electronically on to this little device here and read anything the same as anybody else. I have developed the skills to use the synthetic speech output but it also has a Braille display. If I am a Braille reader I can use this device. I use the synthetic speech, which is a voice that speaks what you ask it to. That is how I read. I also write using the same way. The problem is actually getting access to all the information that is there.

So that is the current information. Whatever information there is, current or future, needs to be made in a format that can be accessible by a range of different methods. The submission that we provided to the committee goes into a bit of detail about the different methods and the different formats that are required in order for a person who is blind or has low vision to access that information. We have looked at future information around planning services. For example, if I want to find out about aged care services, about what the options are for nursing homes or about options for volunteering, the information that is provided generally to the public needs to be made available in a format that can be accessed—electronically, braille, audio, large print and those sorts of areas. Did my answer cover that area?

CHAIR—Yes. One thing that has been suggested to us in terms of the huge amount of government information out there about services, programs, potential funding sources and things, which no-one seems to be able to work their way through, is the development of a national centre for disability excellence or a national resources information centre to pull all this together and hopefully make some sense out of it. What is Vision Australia's take there?

Mr Ah Tong-Pereira—We have actually added in our submission a suggestion that was raised by some of our case managers around having a central portal of some sort whereby service providers, or perhaps even individuals, could access a one-stop shop to get information. I should add that there are two elements of information access. One is being able to use the portal itself. For example, if it is a web based portal, that portal needs to be accessible; not being so means that whatever else you tap into is not available to you. That is one aspect. The second aspect is that all that information will then need to be made available again in a format that can be accessed. In mapping or guiding people through the myriad information that is available, there are those two aspects—how do you actually access the system in order to look and can you read the stuff that you find? So, coming back to your question, we would support some type of central repository or some sort of central system.

CHAIR—In your submission you talk about not being able to access PDF documents.

Mr Ah Tong-Pereira—Yes.

CHAIR—In the Senate we put most of our submissions up as PDF documents, so you would not be able to read the submissions that are put up, for example, on the Senate website.

Mr Ah Tong-Pereira—I will answer you this way. In our submission we indicated that we endorse the Australian Human Rights Commission's position on PDF not being a stand-alone format on websites, the reason being the range of different technologies. Regardless of how a PDF file is being authored or developed, some technologies cannot actually access it. For example, this device will not recognise PDF at all. What we are saying is that, although some people can access some files if they have been developed using specific guidelines on developing accessible documents or accessible PDF files, there are people who will not be able to have access at all, depending on the technology that they use. So, in terms of the Senate committee and government information, we are constantly reminding the government of the Australian Human Rights Commission's position. I understand that there has been work done by AGIMO around this area and I think that they have also come to that conclusion at this point.

CHAIR—I want to follow up another question that Senator Boyce asked earlier. You are addressing comments around planning for people who are vision impaired.

Mr Ah Tong-Pereira—Yes.

CHAIR—There is an issue around people who are hearing impaired and vision impaired deaf/blind. There have been various inquiries and I know you were here earlier so you were listening to part of the evidence earlier, so you would be aware that we have looked into various issues around disability over the years. What has come up repeatedly are the issues around the additional difficulties around people who are deaf/blind. Could you enhance or go a bit further with the answer you gave before relating to the special issues facing people who have both vision and hearing impairment?

Mr Ah Tong-Pereira—Because we provide library services specifically funded for people with a print disability, which includes people who are deaf/blind but also who are unable to follow a line on a page for example or able to hold a book with their hands, we provide the library services there. Specifically my knowledge of deaf/blind issues is not as great but in terms of how people access information, I believe Braille is the standard communication medium for reading for the deaf/blind. There are the tactile Auslan communications between people as well. There are different issues there because the availability of information is reduced again to a certain type of information that can be accessed. For example, if government information or planning information is available in large print or audio but not in a Braille format or in an electronic format that can be then turned into Braille or read on a device that reads Braille electronically, their access is then reduced. It is like a sliding scale of diminishing access.

CHAIR—The committee is particularly focused on ageing or planning for people ageing with a disability and one of the other issues that has been put to us is that there are a lot of people who as they are ageing both their hearing is becoming further impaired and their vision is becoming impaired. In other words they are becoming deaf/blind as they age. I know from family experience and certain older members of my family accessing technology. Is that an additional issue in terms of people being able to use technology as they age with both a hearing and vision impairment?

Mr Ah Tong-Pereira—There are a couple of things in your question. The first one is accessing the equipment to access information. The other part inherent in your question is about actually learning the skills later in life to access the information using those alternate means. There are significant issues around this. We know that the majority of people who are blind or have low vision are older people in our community. Within our own services the median age is 79. We have 80 per cent of our clients over the age of 70. As the population ages the prevalence of people who are older developing vision loss later in life will undoubtedly increase. We provide services that provide skills training to use computers; we provide adult training for Braille literacy. But again there are issues around Braille in terms of sensitivity in the fingers to be able to use Braille as an information medium. Those are the issues there for older Australians accessing information. The issue for the committee to be mindful of is that the mediums we talk about in our submission about how to make information available need to occur regardless of the issues that are faced by people who are older accessing information. What I mean by that is that there are ways of learning skills and there are different technologies that can do different things. For example, DAISY technology that we use in our library services is primarily an audio system so if people are not computer literate, for example, they can actually have that read out to them. Again that poses different issues with hearing loss developing later in life, but again there are skills development options that people can tap into.

Senator BOYCE—Mr Ah Tong-Pereira, what is the cost of the unit you are currently using? How would a person get one?

Mr Ah Tong-Pereira—What was the second part of the question?

Senator BOYCE—How do you access one.

Mr Ah Tong-Pereira—This device I am using at the moment is about three years old and was about $8,000. The newer versions are between $8,000 and $9,000. They actually get more expensive. This unit has an 18-cell Braille display, which means it is not all the way across. I am not sure if you can see that. It is not all the way across the bottom of the display. If I had one with a 32-cell Braille display which would go right across, the price goes up. In our submission we also alluded to the fact that people need to have access to publicly funded equipment. Under the various state and territory schemes, for example the one in Victoria, communication devices such as this are not actually included on the list.

Senator BOYCE—So whether or not they are available is a state issue, is it?

Mr Ah Tong-Pereira—Yes, that issue is state by state. There are other ways of accessing technology through the Commonwealth funded systems. For example, there is a workplace modification scheme funding by the Commonwealth government—the Department of Employment, Education and Workplace Relations—but again you have to be in employment to access that scheme and there are restrictions on it. I think you have to work more than 15 or 18 hours a week and so forth. Coming back to your question about people losing their vision later in life, if they are living solely off a pension and they are not working, then they may not have access to one of these machines at all because they do not have the $9,000 spare to fork out. It is simply a reading and a writing tool. That is a particular issue, and we would actually recommend that either a new scheme be developed or the existing schemes at state and territory levels are expanded to take that consideration into account. Again in our submission we highlighted that. There are significant issues of people being engaged in the workforce throughout their lives. Current figures from our own research back in 2007 found that about 63 per cent of people who are of working age and want to work do not have a job. Of those who do have a job, 46 per cent are only working part time. Again, how does that translate to later on in life.

Senator BOYCE—Exactly.

Mr Ah Tong-Pereira—New opportunities through superannuation accumulations—they all propose issues around funding for equipment.

CHAIR—Would your machine be tax deductible? We have come across this issue before with, for example, hearing aids. We know they are very expensive—$8,000 to $10,000 for some of the top notch ones—and they are not.

Mr Ah Tong-Pereira—I do not believe so. I may be wrong but I do not believe so. Through education that I am doing I have a laptop and I think that has allowed me to claim a certain percentage. But that is a laptop, not necessarily a literacy device. I have a laptop but on top of that laptop I have another program which costs more than the laptop itself. I do not believe that is tax deductible but I can check.

CHAIR—You would need it to carry out your work, wouldn't you?

Mr Ah Tong-Pereira—Yes.

CHAIR—If people need to access technology in order to be able to read documents and access information.

Mr Ah Tong-Pereira—Yes, I guess you probably could but if you are in work you would have access to the DEEWR scheme. I can check that if you need me to.

CHAIR—We can check that.

Senator BOYCE—We will ask the department to worry about it. You said before that your device would not recognise a PDF. Is that a technology issue or is that about two companies not talking to each other?

Mr Ah Tong-Pereira—It is about a few things. The company that makes this device has not caught up with that technology. The biggest issue with PDF is that whether a PDF file is accessible or not is a bit of a lottery. It depends on how you actually create the PDF document itself. For example, if someone scans in a document directly as an image that will not be accessible with any technology because it is an image and not actually a text medium. The problem with PDF is that you have to have knowledge about how to create accessible PDFs in order for them to be good.

Senator BOYCE—The other thing is that you spoke about the web content accessibility guidelines 2.0. Can you tell us a bit about what that means?

Mr Ah Tong-Pereira—WCAG 2.0 is a standard that has been developed by the W3C organisation or consortium, which is an international consortium around web accessibility. What it means is that in order for a screen reader or a Braille display on a device like this to interrogate that information and to navigate easily and effectively over that webpage on a website you have to actually build certain features into the website. For example, to navigate a webpage that has no navigation built in, such as heading structure or the page has been split up into different frames, you would have to navigate from top to bottom to actually read what is on the screen. There are issues again for different graphic interfaces. If there is a graphic that has a picture which says to click here, if it is not in text it will not be picked up by a synthetic speech reader like JAWS. What CAG 2.0 is about is providing guidelines on how to create an accessible webpage, and I believe the Australian government has signed on to the AA rating of that.

Senator BOYCE—Does the FaHCSIA webpage currently meet the guidelines?

Mr Ah Tong-Pereira—I am not too sure but again I can check that. One of the other services we do provide as a fee for service is around web accessibility. We can do audits and create accessible webpages. Accessibility on websites is an interesting thing because a lot of the time, as with the government websites, the webpage is the way in which you actually get access to the information itself. Having an accessible website and webpage is crucial. The second crucial element is actually having the downloadable information accessible as well. There is also the other element of people who are blind or have low vision and are also public servants. The mechanisms which people have developed for the information that goes out need to be systems that are mindful of staff members who need accessibility built in to the inhouse systems that they use. There are two sides to that perspective. There is the content developer's side and the need to have access through different mechanisms, and then there are the consumers of the information itself.

Senator BOYCE—Thank you.

CHAIR—Thank you very much for coming in. It is very much appreciated.

Proceedings suspended from 10.29 am to 10.53 am

BEDFORD, Ms Helen, Branch Head, Disability and Carers Policy, Department of Families, Housing, Community Services and Indigenous Affairs

HARTLAND, Dr Nick, Group Manager, Disability and Carers Group, Department of Families, Housing, Community Services and Indigenous Affairs

CHAIR—I now welcome officers from the Department of Families, Housing, Community Services and Indigenous Affairs. Information about parliamentary privilege and the protection of witnesses and evidence has been provided to you. As departmental officers you will not be asked to give opinions on matters of policy, though this does not preclude questions asking for explanations of policy or factual questions about when and how policies were adopted.

We have your original submission, submission No. 20, and we also have the answers to the questions that we had placed on notice. Thank you very much for that. I would like to invite you to make an opening statement and we will then ask you heaps of questions.

Ms Bedford—Thank you. I would just like to give you an update on some of the policy that we flagged at the last hearing. Last time I was here I provided information on the initiatives the Commonwealth and state and territory governments had in place, or had under development, which would improve service delivery options for people with disability and carers and therefore increase future planning options in the short and longer term. I would like to provide an update on the progress of some of those key initiatives since my appearance in November.

The key work in progress has been the National Disability Strategy, the National Carer Strategy and the implementation of the National Disability Agreement, which are taking into account the need for people with disability who are ageing, and their carers, to plan for the future. I am glad to announce that the National Disability Strategy was formally endorsed by COAG on 13 February this year. That is the first time in Australia’s history that all governments have committed to a unified national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes. The strategy will provide public policy across governments and it aims to bring about change in mainstream services and programs as well as in community infrastructure. It includes six broad policy areas to improve outcomes of people with disability, their families and carers.

The broad policy area that is of particular relevance to this inquiry is economic security. This outcome area is about people with disability and their families and carers having economic security to enable them to plan for the future and exercise choice and control over their lives. Areas for future action under this policy area include developing innovative approaches to future financial planning, including private provision. We will also focus on developing innovative options to improve affordability and security of housing across all forms of tenure. In the first year of the strategy the focus will be on building the foundation for implementation, which will include engaging mainstream policy areas to ensure they give effect to the strategy’s objectives in their area of responsibility. Areas for future action will be prioritised in collaboration with people with disability, their families and carers and other key stakeholders.

I would also like to mention that as part of the NDS, the National Disability Strategy, the government asked the Productivity Commission to conduct an independent inquiry into the cost benefits and feasibility of a national long-term care and support scheme for people with disability. The draft report on that inquiry is due for release on 28 February, next Monday. Its final report is due in July 2011, and at that stage all governments will consider the findings.

The other area is the National Carer Recognition Framework, which we are working on with our colleagues from DoHA. I am pleased to confirm that the Carer Recognition Act 2010 commenced on 18 November 2010. The legislation recognises and acknowledges the valuable contribution that carers make to Australian society and complements carer recognition legislation that is in place in some states and territories. The cornerstone of the bill is a statement for carers which sets out ten principles that Commonwealth government agencies and funded organisations need to adopt when developing policies and delivering services for carers or the person they care for.

The second element of the framework is the development of the National Carer Strategy, which is progressing. It will set out an agenda to guide policy development in service delivery for carers. National consultations were held late last year and an online submissions process concluded in January this year. There will be a summary report on those workshops, which will be considered by ministers. We are planning to delivery the strategy in the first half of 2011. In developing the strategy, consideration is being given to responding to the needs of older carers, in the context of the disability service system and the broader system of supports for carers. We are working with our state and territory colleagues as well, under the National Disability Agreement, to consider the needs of older carers. At our last hearing I flagged that we were working on a national stocktake of future planning initiatives for families of people with disability. We have gone back out to states and territories, and they are currently revising their input to that stocktake. That will then go to ministers for agreement to release or for them to consider.

CHAIR—Do you have anything to add, Dr Hartland?

Dr Hartland—No.

CHAIR—And Ms Bedford, you have finished your statement?

Ms Bedford—Yes.

Senator BOYCE—Will you be able to answer questions, Ms Bedford, from Ms Winkler’s area or not? I understand she is not here.

Dr Hartland—We apologise for that, Senator. We were not able to get a representative from Mental Health in FaHCSIA today. We will certainly have a crack at it, but we may come to the point where we have to take them on notice.

Senator BOYCE—Ms Bedford, you were talking about delivering strategy in relation to older carers in the first half of 2011. Could you explain what that means?

Ms Bedford—It will be part of the National Carer Strategy, so consideration of—

Senator BOYCE—So what will actually happen?

Ms Bedford—We have had the consultation process. We had a discussion paper and then a consultation process and at the moment we are working with our colleagues in Health and Ageing to develop an agenda, as I said, to take forward around the National Carer Strategy and that will go to ministers for agreement.

Dr Hartland—So in concept the National Carer Strategy is somewhat similar to the National Disability Strategy. It is a document that sets out the government's vision for carers and as a mechanism for getting alignment across Commonwealth departments and with states to improve outcomes. What will happen is the release of the strategy and we are still working on the details of that.

Senator BOYCE—So we are talking about delivering a concept, not delivering programs based on that concept. I was just getting excited about actual services in early 2011. Can I ask you about an issue that has arisen I think since our last meeting and which I had not been aware of. I will read to you part of a submission which we have taken recently. It says:

> My wife and I reside in Broadbeach on the Gold Coast and our son resides in South Tweed Head, NSW. We went through the process of trying to move him into QLD to be close to us and his sister ... but it all fell apart when QLD disabilities informed us that when the portability funding from NSW ran out in 12 months, they would not be able to promise any further funding and also that no suitable accommodation was available.

What involvement does FaHCSIA have in that interstate question and what is being done to assure parents that they do not have to stay forever in one state to make sure the package stays the same?

Ms Bedford—The disability officials group—made up of the Commonwealth, state and territory disabilities groups—is a policy research working group that meets regularly. Portability has certainly been on the agenda for that group. There has been a move to re-look at portability policy. States have agreed that people would move with their funding for a year, and that is generally agreed between states and territories. Then the person is considered in the mix of the relevant receiving state or territory program funding and guidelines about what their level of funding would be.

Senator BOYCE—So the current policy is for 12 months?

Ms Bedford—There has been work and there is certainly goodwill about assisting people moving and the Commonwealth is part of that working group and working with our state and territory colleagues to progress that work so that it does improve possibilities of transfers between states.

Senator BOYCE—So what you would expect is that, provided there is agreement of some sort, a recommendation would go from the disabilities officials group to—

Ms Bedford—Ministers.

Senator BOYCE—To the COAG ministerial body. Is that right?

Ms Bedford—To the relevant minister or council.

CHAIR—This has been an issue for a significant period of time, so I cannot remember when the agreement was made for the year—

Ms Bedford—It was 2006, I think.

CHAIR—So that was four years ago. What progress has been made in terms of fixing this issue, because this is another family that has been split because they have not been able to resolve the issue between New South Wales and Queensland? How close are we to getting this fixed?

Ms Bedford—I would hate to say that it is very close to being fixed. It is still an issue, but there has been agreement about what aids and equipment can move with people, because that was another issue—around what equipment belonged to which system. It is becoming easier to move aids and equipment. It is a priority for the disability officials to work through so it is less complex than it used to be. There are more systems in process to assist people to move, but I would not say all the problems have gone away.

CHAIR—I am not trying to be rude but it has been a priority for a long time, and it does not help people out there. As you said, this group was started four years ago and we still are not any closer to the situation being permanently fixed.

Ms Bedford—We use what influence we have to progress this but at the end of the day it comes down to a state government agreeing to take on the funding of a person’s care and support from another state government or territory government.

CHAIR—I get the picture.

Senator BOYCE—So its very difficult to see how it can be fixed forever. If you are expecting a state government to take on the liabilities of a seven-year-old with severe disabilities then they are probably not going to agree, are they?

Ms Bedford—There have been a number of people and children who have been able to move, and have been assisted.

Senator BOYCE—Anyone can move—

Ms Bedford—With support.

Senator BOYCE—And keep their package?

Ms Bedford—Yes.

Senator BOYCE—How does that work?

Ms Bedford—Through negotiation and working through the issues between the two governments.

Senator BOYCE—So in that case what has happened is that the ‘receiving government’—for want of a better term—has said, ‘Yes, this is the package we can offer you when your old package runs out, and we guarantee you that for three years,’ or whatever they would normally do. Is that the case?

Ms Bedford—Yes.

CHAIR—So we have negotiated a national strategy for a national approach but we have not fixed up some of those basic portability issues.

Ms Bedford—Yes.

CHAIR—And how have those negotiations happened? Has it been individuals negotiating with departments?

Ms Bedford—No, there is a contact point in each state or territory government around portability. Part of that working group has been making sure the right processes are in place to simplify possible approaches to the move from states and territories to other states and territories. There is now a network of those contact points so that they talk to each other frequently and they know what people want to do and how they want to move. So there are a number of process oriented things which are going on to assist people to move.

Senator BOYCE—How many successful moves would have been negotiated?

Ms Bedford—I do not have those numbers.

Senator BOYCE—Is it possible to get them?

Ms Bedford—I would have to ask the states and territories for those numbers.

Senator BOYCE—Thank you.

CHAIR—While Senator Boyce is finding her next group of questions, can we go to ADEs and employment. You will be aware of a lot of the evidence that we have taken about retirement. This is intimately involved with planning for ageing with a disability. We have taken a lot of evidence that a lot of ADEs are not able to plan; they do not have enough resources to address retirement. And this is not only affecting the people that need to retire, but it is also taking up places—that is a crude way of putting it—which means it is stopping younger people being able to come into employment.

Senator BOYCE—And making the places less productive.

CHAIR—And making the places less productive. So there are a whole lot of issues around there.

Senator BOYCE—When the criteria are that they should be.

CHAIR—I am aware there are a couple of pilot schemes. I am also aware that there are some organisations that are just going ahead and doing it and that is having a significant financial impact. So can we talk about where you are up to, where governments are up to, and perhaps also look at how that is factoring into the national strategy?

Dr Hartland—Yes, Senator. We are aware of the issue. The workforce in ADEs, like the workforce across Australia, is ageing. So we are seeing more issues around people moving into both normal retirement age and we are also seeing more people whose disability means that their productivity is falling earlier than you would expect in a normal workforce.

Senator BOYCE—It is a sort of premature ageing issue really, isn’t it?

Dr Hartland—Yes, that is right. We are aware of this issue. We have, I think, three pilots that are looking at how you might get these people into mainstream community services and whether that is a way of supporting them to move into retirement.

CHAIR—What do you mean about ‘mainstream services’?

Dr Hartland—Local services like senior citizens clubs—places like that that would organise activities. The other options are around state services but there are some difficulties there because these people, in many cases, will actually have more functioning than the people who would normally go into the state services. There is a bit of a gap between the ADE workforce and the state services, so that is a difficulty in this area.

The pilots are not complete at this point and we are intending to evaluate them. It is looking as though there are issues around the capacity of community groups to easily pick up a new cohort. We have been optimistic about, say, a group that has been set up to provide activities for people with Alzheimer’s or some other ageing-related impairment because we thought that the kind of functional impact would be quite similar. But it does look as though there are some issues about easily putting the people who come out of ADEs into those groups. But we are not quite at the bottom of the pilots yet and I think we need to let them run and see whether that is an implementation issue that they can get over when they do it or—

Senator BOYCE—Where are the pilots, Dr Hartland?

Dr Hartland—Victoria, New South Wales and the ACT.

CHAIR—And what is the time frame on those?

Dr Hartland—They are to be completed by June 2011.

CHAIR—So we are just about near the end. And how long have they been going for?

Dr Hartland—They have been running for about five months.

CHAIR—Okay, so they are relatively—

Dr Hartland—They are relatively new and fairly short term. Some of the issues that are emerging are simple. Some of them are about transport and some are about support needs—requiring a person to be with that person—and the community groups that were set up for other more mainstream people cannot easily do that. As I said, there is an issue about it not being as easy just to put them in a state service that would be for people with a disability. Those services are oversubscribed anyway, so there is the same problem we see elsewhere through the system. So we are not quite ready to conclude our thoughts on how the pilots are going and whether that is the right approach, but we will have to soon obviously, given that they are coming to an end in June.

I guess the other thing to say is that disability officials have been talking about both transition from ADEs to retirement and transition from schools to ADEs. Again, that is not quite crystallised at a point where we would be able to provide you with a paper yet but work is going on. People are aware of those issues so it has been actively considered by disability officials.

CHAIR—I have got a number of issues around that. The other issue that has been clearly put to us is around people who are having to phase out of retirement and are staying at home more. If these people are in supported accommodation, a lot of the support in supported accommodation finishes at, say, nine o'clock in the morning and does not start again till three. So these people are at home with no support because the other services that you have just talked about are not there either. Is that one of the issues that has been picked up?

Dr Hartland—Yes, we are aware of that issue.

CHAIR—Have you done any data analysis on the number of people now—and you will have seen the evidence—that are already funding retirement options and alternatives out of their own pocket? They are not able to access funding for it. Have you got the numbers for people already in this position and those who are likely to be in this position in the future? Have you done some analysis on the types of funding that are going to be required?

Dr Hartland—We have a feel for the age of people in ADEs. The proportion of people working in ADEs who are over 50 will increase from 21.2 per cent to 32.5 per cent in five years time and to 50 per cent in 15 years time. So we have done some analysis of trends in the ADE workforce. That is a larger group than the problem you were just identifying of people who are both in an ADE and in supported accommodation. If they were not in an ADE, they would have a problem if the supported accommodation did not provide those services. I do not have a feel—

Senator BOYCE—And they are not funded.

Dr Hartland—I thought I would give you that broader number for context, but I do not have that figure in front of me.

CHAIR—Those who are not in supported accommodation may be living with ageing parents. So you have got the issue of them coming home to ageing parents who may not be able to manage when they are at home and, as a consequence, they are also going to need some form of accommodation. That is another layer of complexity.

Dr Hartland—Yes. I think those types of things indicate a need to take action. I just want to go back to something you said about ADEs funding it out of their own pocket. I would want to pause on whether that was the right way to describe it if those persons still attract Commonwealth funding and Commonwealth support.

CHAIR—I take your point. They are saying that it is costing them and that they are putting that funding in. It may not be all of it, so I have probably articulated that wrongly.

Dr Hartland—Program managers occasionally get prickly about—

CHAIR—I accept that. The point is very well taken. But they are saying that it is actually costing them not only to set up new programs—because they do not want to just have nothing—but also in lost productivity.

Dr Hartland—I think that raises a very interesting question.

Senator BOYCE—Wasn't it in Newcastle that a group was running raffles so they could allow these people to continue to work part time because there was nothing else for them to do?

CHAIR—And they have set up recreational programs. Again, I will need to look back at the evidence, but I think it was in Newcastle—it was certainly in New South Wales.

Dr Hartland—We are aware of that, but that may not be a terrible solution either. I know there is a funding issue there about how the government supports that appropriately, but many ADEs are part of larger organisations that run a series of programs. Actually having some flexibility in the business that allows them to meet people's needs as they change might not be a terrible position to be in. But the question you are raising is whether our funding mechanisms support—

Senator BOYCE—It is also the fact that once people reach retirement age they do not want to go out and do something every day. They might very well want to sit and watch daytime television sometimes.

Dr Hartland—There are a lot of us.

Senator BOYCE—Heaven forbid we should act like that!

CHAIR—I was just thinking that on daytime television you get some pretty nasty stuff.

Senator BOYCE—I did hesitate before I said it.

CHAIR—I know that organisations are starting to plan and develop alternative approaches—

Senator BOYCE—Stopgaps really at the present time because there is nothing else they can do.

CHAIR—Stopgaps, yes.

Dr Hartland—I appreciate that the funding silos that ADEs are a part of can be a bit inflexible, and you see that in a number of areas. You also see it in the distinction between outprograms and the open employment programs that are run by DEEWR. So there are a whole lot of boundary issues that people are working on and are aware of. ADEs being integrated is an option. One of the solutions might be that ADEs are more integrated across different areas. That is not a final view from the department. It is speculative and so probably falls outside the terms of reference of what we normally offer. It is a long-winded way of saying that, as you are aware, there is a process looking at a vision for ADEs that is also going on and those types of issues are being examined in that process. So the flexibility of funding, how ADEs should look in the future, whether they reach back to schools and whether they reach forward to retirement—those types of issues—are being considered in that process as well.

CHAIR—It has been put to us by a number of witnesses, both on the record and informally when chatting afterwards, that they are concerned about not only the longer term issues but also some of the short-term funding issues. What are the time frames at the moment for trying to come up with a longer term solution and is there any consideration being given to dealing with some of the more immediate short-term issues of funding and funding shortfalls?

Dr Hartland—We are always interacting with the sector about what their needs are. We will have to offer a new contract at the end of this financial year to ADEs, so issues about funding and the make-up of the appropriation, the make-up of the funding for ADEs, are part of the normal course of events. Certainly, in the short term we are actively talking to the sector and planning for next year at this stage. The long-term or the vision process is due around the middle of the year I think, but we are certainly hoping to start interacting more with government around the middle of the year. I am just pausing because I am not certain whether that will crystallise in the public or at what point you would expect to see a public result. I might have to take that on notice, I am sorry; I know I should know that.

CHAIR—If you could, that would be appreciated. I do not want to put words in your mouth, but the new contracts will be negotiated shortly, I would think, so do I understand that you may be considering issues around the need to address this issue of retirement?

Dr Hartland—That would be major surgery on the way we would fund ADEs. We are not contemplating a major change in funding for the next round of contracts. These issues about retirement and the nature of the sector would have to be dealt with in the vision.

CHAIR—This is my final question on ADEs. For the pilots that are running until June, what is the process after that? Is there a possibility that, if they are successful, those pilots will be funded again or will they stop and you will carry out an evaluation? Then what happens from there and how quick is the evaluation?

Dr Hartland—At this point the pilots will end. It is always a difficulty when you end a pilot as to how you then deal with the people who have been involved. We have not come to that issue yet, but we are aware of it. The process will be that we will evaluate the pilots and then we will have to interact with government about what way they want to take this issue. Broadly, at the time it will allow us to think about that in the vision process as well. The timing will gel with talking to government about its vision for ADEs.

Senator BOYCE—We were told this morning that special disability trust forms are not downloadable from Centrelink's website and that you have to go to a Centrelink office to get one. Is that because you asked Centrelink to do it?

Dr Hartland—I would be extremely surprised if we instructed Centrelink not to make downloadable forms, so I suspect not. I can double-check, but it does not sound like something we would require of Centrelink not to make a particular form downloadable. I can understand why it must be frustrating.

Senator BOYCE—Because FaHCSIA have asked them to, so we will ask Centrelink why it is that way.

Dr Hartland—I suspect it is because the traffic on the special disability trust forms is not as high as, for example, disability support payment or age pension.

CHAIR—The carer payment and carer allowance is what they were talking about.

Dr Hartland—Is it?

CHAIR—I need to double-check, but they need to fill in that form for the SDTs. That is what I thought they were talking about, so we will need to double-check that in the *Hansard* and chase it up with Centrelink next week in estimates.

Senator BOYCE—One assumes also that if a form is hard to download there is going to be less and less traffic on it.

Dr Hartland—I had better not speculate. We had better chase whether there is a reason or whether it is just the volume of the forms or maybe the complexity did not allow them to be put in the right forum for a download. I do not know.

CHAIR—The other issue we were talking about with the Mental Health Council was how you deal with the special disability trusts in mental health and mental illness. They were saying it is very difficult—the criteria do not work for people caring for somebody with a mental illness. You may not be able to answer some of our questions about mental health because Ms Winkler was not able to join us. We will ask DoHA about it. We may put some more on notice. With particular issues facing people caring for people with a mental illness, the episodic nature of the illness and things like that, how are you dealing with that in particular with special disability trusts? There are also other issues out there we want to explore.

Dr Hartland—On the issue about mental illness and special disability trusts, broadly we are aware of the issue about the episodic nature of mental illness and whether the rules around disability support pension and other payments work well in that context we are aware of.

CHAIR—Did you say you are aware of it?

Dr Hartland—Yes. I have not heard the issue around special disability trusts and mental illness raised before. We may have received representations on it and I would have to check with the branch.

Senator BOYCE—They were making the point that families who had provided for their adult with mental health problems by buying two units were then penalised by not being able to access the pension because of the deeming provisions. It was five years in one case. Then they found out about the special disability trusts, which would have solved this problem, but then they found they did not fit the criteria of the special disability trusts.

CHAIR—That is a common issue, as we know, around having already purchased a property for your son or daughter and then not meeting the criteria for the special disability trusts. So they were saying that it continues to be an issue for people looking after someone with mental illness, but the issue was particularly around qualifying. As you know, to qualify under SDT you have to meet the eligibility requirements for carers allowance or carers payment and they are saying that many of the people they work with and their consumers do not meet the eligibility requirements because of the episodic nature of their illness and other issues there as well. It sounds as if this has not come up too much before.

Dr Hartland—I suspect that is right—we will check, I think it is true to say that when we established special disability trusts we did have, if you like, an image of a permanent, ongoing disability, so it was about a lifetime provision. I think also it is true to say that we did not anticipate that they would be a vehicle for people caring for someone with an episodic illness. So we are really now getting to—but we will check with the branch—an area where there is not a settled policy position. There would be pros and cons either way though. There are often pros and cons either way. There may be some reasons why you may not want special disability trusts to be for an episodic illness, but I am starting to get more speculative even than I was five minutes ago.

Senator BOYCE—I think that the issue here was particularly about when parents are getting older and know that they are not going to be around to stop exploitation or other things happening to people who are often vulnerable, although not always vulnerable, that there is an attraction about having a house, a home, that no-one can take away from them.

CHAIR—The numbers were pretty scary in terms of that, and they tabled the latest reports of their carers. I think FaHCSIA funds the work they have been doing around mental health carers and reports and needs issues for mental health carers. Sixty-eight per cent of the carers were ageing and 62 per cent of adult consumers, so we are talking about an issue that is arising not in the future but now. So it is very important for our inquiry here about planning for ageing for people with a disability; these consumers and carers are right there now. I have spent a lot of time working on special disability trusts and we really have not come to terms with the issues around mental health carers and consumers.

Senator BOYCE—It is a difficult one.

CHAIR—I acknowledge it is a very difficult one, and there are added complexities—we talked about that this morning so you can see it in *Hansard*—around where the consumer does not want their carer involved in decision making during periods when they are unwell or in fact when they are well. So we appreciate that, but what carers are now identifying is that this is a significant issue for them. Maybe you could take it on notice, perhaps looking at *Hansard* first. We appreciate that we have just dropped it on you. I suspect we may be chasing it in any case during estimates next week as well under special disability trusts.

Dr Hartland—I certainly will check whether the issue has been raised with us. It would be helpful, given that we are coming up to estimates, to refresh our memories about the rules as they relate to this issue because—

CHAIR—I can tell you now—some advance notice—that it is on the agenda for next week!

Dr Hartland—I will give you a download on what the rules say. It may be that the rules are clear but the issue about whether this was a vehicle for that group has not really been discussed, in which case we will get to a situation where it is a matter of a policy horizon we quickly come to.

CHAIR—I appreciate that.

Senator BOYCE—Can we just go back to the national stocktake. In the question on notice, you have provided us with a list. Did I hear you say, Ms Bedford, that the list is being revised?

Ms Bedford—The draft stocktake has gone back out to the states and territories and they are updating it because—as I think I mentioned last time—organisations change or come on or go off. I think we agreed it was a fairly complex moving area.

Senator BOYCE—I would be interested to see the final list, although I realise that is only going to be final at a point in time. I think the Mental Health Council of Australia told us this morning about a couple of other organisations that are not on that list. You say here that the paper you are doing out of this is to be finalised and provided to the disability policy research working group in early 2011. Has that happened?

Ms Bedford—The paper is out there. We have sent it out to states and territories and they are updating it so it has not been finalised. It is in the process of being finalised.

Senator BOYCE—So it is not just the list per se that is being updated.

Ms Bedford—No.

Senator BOYCE—What else is being updated then?

Ms Bedford—The information and if there are any policy drivers that have changed within states and territories. So it is not just a list; the paper itself has more information in it.

Senator BOYCE—Around barriers to future planning and the like?

Ms Bedford—Yes.

Senator BOYCE—You are looking at best practice features of future planning programs. It sounds like a really useful report. When are you anticipating that this would be finalised?

Ms Bedford—We are hoping to get it back in the near future and then we will have to seek agreement to go to ministers to get it signed off.

Senator BOYCE—So there are no deadlines about any of this?

Ms Bedford—No. But it is a tool that we want out there and we think it is a useful tool so we are hoping to move that fairly quickly.

Senator BOYCE—I also want to ask you about your saying that 59,000 people—and again from questions on notice—in 2006-07 were reported to be on individualised funding arrangements and yet we have numbers showing that people with severe and profound disabilities are up to over a million already. Isn’t that the case? I think it is 1.6 million. Can you talk about the disparity between those figures?

Ms Bedford—On individual—

Senator BOYCE—The disparity between the fact that we have 59,000 people on individual funding arrangements and yet over a million people with severe or profound disability characteristics. ABS statistics say we have 1.6 million or am I misreading it?

Dr Hartland—I am sorry, I do not have the SDAC in front of me. Part of the difference might be the over and under 65s so the individual funding package is of more relevance to people in the special disabilities services. If that SDAC figure is severe and profound for the population, you would want to take quite a few off to get to the sort of notionally working-age population. Then you have the issue about access to specialist services so not all people with severe and profound disability are accessing state services that would be of the nature that you would give an individualised funding package to. That gets us to the question of people who live with their families and have a very substantial informal care provision. Many of them may be accessing lower level services. When we looked at it for the question on notice, we were coming up with a figure of around 20 per cent of people in community support were on an individual funding package so you probably could reconcile it.

Senator BOYCE—Twenty-seven per cent were service users and that was 2006-07, wasn’t it?

Ms Bedford—That was around getting the data source that would give us the individual funding number, the information that you were seeking.

Senator BOYCE—I guess my question is: what does that statistic tell us, if anything, about unmet need?

Dr Hartland—It does not directly reflect on the question of unmet need, but we know, whichever way you look at it, there are a substantial group of people who would like higher level services than they are currently getting. I do not think there is anyone saying that there is not a level of unmet need. There is some dispute about how best to measure it. We are talking about a type of funding arrangement within the group that get access to funding. I am running out of steam, Senator; I am sorry. From the look on your face it does not look like I have actually answered your question.

Senator BOYCE—I am reading ‘better measurement of need’ in the National Disability Agreement yet we are told that the methodologies for assessing unmet need are a state issue and not known to FaHCSIA. I am starting to shake my head.

Ms Bedford—I don’t think we were saying that.

Dr Hartland—That is a fair point. Let me just clarify it.

Senator BOYCE—You think I have misinterpreted an answer then?

Dr Hartland—Perhaps I was not clear enough. We have been working with state officials on a NDA priority called better measurement of unmet need. There is a national report in draft form on that. I said there were a number of methodologies. That report takes quite a sophisticated actuarial approach to measuring unmet need. There are other approaches around and you get slightly different answers when you look at them. The unmet need report is going to go to ministers again soon—around the middle of the year—for them to consider publishing it. Actually we are quite happy with the national progress on measuring unmet need.

Senator BOYCE—Which bit are you happy with? You say you are happy with the progress.

Dr Hartland—We are happy we have an agreed methodology to estimate how much unmet need there is and that the approach that ministers have agreed to, and we are now updating the data for, gives us a robust estimate not only currently but into the future about pressures on the system.

Senator BOYCE—Will that cover planning needs or service use needs?

Dr Hartland—There is a separate bit of work on benchmarks for service provision that covers people with an individual funding arrangement.

Ms Bedford—That work is working in with the better measurement of unmet need. We are using the data and the methodology for the unmet need model to better inform the benchmarks, so they are all linked.

Dr Hartland—I would not want to give the impression that we are unconcerned about a national approach to measuring unmet need. We have been working on this with the states. That is progressing, in our view, quite well. But the issue of who gets access to an individual service package is a subset of the wider question of unmet need for care and support. That was what I was trying to pull apart by talking about different approaches.

Senator BOYCE—It would be my experience that most people would prefer individualised funding to block funding, but I cannot justify that comment. It is strictly anecdotal. You may be able to comment on it yourself.

Ms Bedford—Certainly if you look, as we do, at the state and territory budgets, there has been a rising commitment around individual funding. New South Wales funding—I have to check whether it is 2013 or 2014—will all be available on an individual basis, which is quite a move forward. Queensland and Victoria have made announcements in a number of budgets about increasing their individual funding options. There is certainly a move for person-centred or individual approaches to funding.

Dr Hartland—We would agree that there are large policy benefits to be had in this area. As Ms Bedford said, the advocacy and disability community certainly see large policy benefits. In fact, the state government departments generally think this is the way forward because it leads to benefits in terms of people feeling control over their life. It leads services—we hope—to be more responsive to people's needs. There is one thing to be a bit cautious about when taking that figure for people who currently get an individual service package and comparing it to either the pool of people who get some type of service response or those who have a severe or profound activity limitation. If you are being cared for by your family, you may have a severe or profound activity limitation and you and your family may want to have an arrangement whereby you are cared for in the family home, and so the service you need is effectively a home and community care service that can be funded out of a block grant. That could be two hours for someone to come in and clean or to do some other specific task. You would be very surprised if that were recorded as an individualised funding package; but, nonetheless, it might be the funding package that properly suits your individual circumstances. I guess that is an analytical way of saying that we need to be a bit cautious about taking—

Senator BOYCE—Individual funding is being used that is not in individual funding packages.

Dr Hartland—That is right. That is what I was—

Senator BOYCE—I will accept that as a wake-up.

CHAIR—I think we are going to have to move on.

Senator BOYCE—Yes.

CHAIR—One of your answers to evidence we received was around pension eligibility and the DSP. If I remember correctly, someone gave evidence that they had experienced a drop in services because they had to go onto an age pension. They had lost some of the services and support that came off DSP. In your answer, you said that people can stay on DSP; they do not have to go over to the age pension. The way I interpreted what we had been told was that they had been required to go onto the age pension. So you are saying—

Senator BOYCE—I think it might be around how we were told—

CHAIR—Yes, it might have been around how we were told.

Dr Hartland—We would in general see the age pension as the appropriate payment for people over 65. People are asked to nominate whether they wish to transfer to the age pension but we do not require it. People need to look at all their circumstances because the age pension and the DSP do have some differences. Even within the income support system there are some differences. So people need to consider which payment best suits their needs. We do not require you to go onto the age pension, although once you are of age pension age you cannot apply for the disability support pension. I do worry about other service systems leveraging their eligibility criteria off income support criteria.

Senator BOYCE—Sorry, say that again.

Dr Hartland—I think there is a policy issue, so I will try to be more formal. We are aware that many services take pension eligibility of one type or another to be a kind of eligibility criterion for their services. I think there are policy reasons to think that has some disadvantages. The pension eligibility criteria that we have worked on for a number of years was to make sure that pensions worked well, and we would not necessarily assume that that was the right approach to take to other services. We know that that happens and lots of services do not have the capacity to run a separate eligibility process and so the pension is a convenience. It would be interesting to get some details about some of these cases if you had them put to you, because prima facie you would not say eligibility for DSP is necessarily the right eligibility for a service response.

CHAIR—If I understand you correctly, you are saying that it is not the government process requiring people to swap but the service providers in various states who in some instances are saying that a person’s eligibility hinges around this.

Dr Hartland—Yes. We certainly would not require other services to have DSP as an eligibility criterion.

CHAIR—That has cleared that element up.

Senator BOYCE—Do you have the figures for people who were on DSP who went onto the age pension and for those who stayed on DSP? You do not necessarily have to provide them now.

Dr Hartland—We may actually have them now, but we can certainly take that notice if Ms Bedford cannot find them.

Ms Bedford—We might have to take it on notice.

CHAIR—That would be appreciated. Thank you.

Dr Hartland—Around 18,000 are on disability support pension and over 65.

CHAIR—18,000?

Dr Hartland—Around 18,524 as of December.

CHAIR—So they have stayed on it and are over the age of 65?

Dr Hartland—Yes. But we do not know the other side of the question, which is: how many changed?

CHAIR—Yes. If you could take that on notice.

Dr Hartland—We can certainly find that.

CHAIR—When the pension age moves from 65 to 67, you say that people will have to wait until they are 67 to go onto the age pension but that they could go onto a DSP.

Dr Hartland—That is right. They will be able to apply for DSP. The cut-off for applying to DSP is linked to the age pension age; it is not separately set. When the age pension age is 67, people can apply for DSP up to the age of 67. The current policy is that you do not have to move from DSP; it will continue to apply. So, effectively, those who are on DSP and still need DSP will be able to access it at 66 and 67. There were 35,632 people who went from DSP to the age pension.

Senator BOYCE—That is interesting. So basically one in three do not change.

Dr Hartland—No. The 35,000 figure is over less than a year; it is from December to March. So it is a quarter, but the 18,000 is the total number of people over 65.

Senator BOYCE—All together.

Dr Hartland—All together.

CHAIR—Senator Boyce has another section that she wants to move onto, but before she does that we have a couple of issues here that go to the Department of Health and Ageing but also cross over to you. These issues are around the intersection between disability and ageing. Are you able to stay a little longer while we talk to the Department of Health and Ageing?

Dr Hartland—Yes.

CHAIR—We are not finished with you yet. I am just clarifying—

Senator BOYCE—When we are finished, you are not finished.

CHAIR—Yes. I was just clarifying whether you were available to say.

Dr Hartland—We are at your call.

CHAIR—If you were not able to stay, I probably would have launched into the borderline issues, but if you are able to say then we will proceed and call on you if we need you again. Is that okay?

Dr Hartland—Yes.

Senator BOYCE—Two things that have come up over and over again is what is perceived to be the lack of good data around disability and the differences between long-term impairments and short-term impairments et cetera. For example, we do not know how many people with Down syndrome there are in Australia. There are also the sorts of distinctions that might give people the chance to talk about specific disabilities or specific characteristics of a disability that could mean we need a different policy approach. There has been a lot of material around lack of data.

The other suggestion that has come up over and over is that no-one has got their head around what is available in programs and funding at state and federal levels. In fact I think someone who works full time as CEO of a disability organisation said, ‘I don’t really understand it.’ Suggestions have come up about centres of excellence, one-stop shops and national points where everyone can get everything. Could you comment on those two points from the department’s perspective?

Dr Hartland—I think they are separate. The implication was that you would have a one-stop shop for both data and services. It is hard for me to visualise what that would look like or how you would manage it.

Senator BOYCE—I think the one-stop shop is more about the information than the data. But obviously it was felt that a lot of the spits and spots of programs are around the fact that to properly understand the demographics there is not always the data about people with disabilities that we need.

Dr Hartland—Yes, the data issue is a problem. We have a 2009 survey of disability and ageing—the first one since 2003. That does make it hard for us and, we recognise, the community to keep monitoring trends in the population and to understand what is happening to people; but we do recognise that is an issue. The one-stop shops are an issue now. There is some work under the NDA about simplifying access, which I think we have talked to you about before.

Ms Bedford—Also, that is coming up across the aged disability sector. Our colleagues might be able to talk about that as well. The issue around data and clearing houses and some sort of institute or some sort of structure that could handle that has come up. Under the NDA we now have a research and development fund with the states and territories for $10 million over five years. Towards the end of last year we had a national roundtable, which had been built up from state and territory roundtables, to identify research priorities. Certainly a number of people at the local and national roundtables raised that sort of issue. They wanted it to look at data as well as best practice around service provision and other related research et cetera. That work is being drawn together at the moment. Once again, that is a process which is taking place at the moment and which will end up back with ministers for consideration. Certainly, how we would go forward with that research and that agenda has been raised and considered at a national roundtable.

Senator BOYCE—And what is the next step there?

Ms Bedford—The next step is to take it back to disability officials and then to ministers. It has been quite a task putting them together, though.

CHAIR—Thank you very much.

[11.59 am]

BALMANNO, Ms Rachel Ann, Assistant Secretary, Home and Community Care Reform Branch, Department of Health and Ageing

HARTLAND, Dr Nick, Group Manager, Disability and Carers Group, Department of Families, Housing, Community Services and Indigenous Affairs

MACKEY, Mrs Tracy, Assistant Secretary, Community Programs and Carers Branch, Department of Health and Ageing

SMITH, Mrs Carolyn, First Assistant Secretary, Ageing and Aged Care Division, Department of Health and Ageing

CHAIR—Welcome. I know that you all know the information about parliamentary privilege and the protection of witnesses and evidence. As departmental officers you will not be asked to give opinions on matters of policy, though we can ask you about explanations of policy and factual questions about how and when policies were adopted. We do not have a submission from you. We have had a large number of issues come up that obviously fall in your bailiwick. That is why we asked you to appear and we thank you very much for coming. If you would like to make an opening statement you are very welcome to and then we will ask you some questions.

Mrs Smith—I will make a brief opening statement but we will then be in your hands for areas that you want to explore. We welcome the opportunity to come and contribute to the inquiry. The department oversights a number of programs that provide support for older people with a disability, and senators would be well aware of those—the Home and Community Care program, community aged care packages, the National Respite for Carers program, and residential aged care. We also put in a significant program effort on assessment and information to connect older people with a disability to the services that they need through programs such as the Aged Care Assessment Program and Commonwealth respite and Carelink centres.

You would be aware that we are currently going through a significant reform agenda in the aged-care area. It is also fair to say that there is more to come. Aged care was a significant feature of the reforms agreed to by COAG last April. There was a bunch of aged-care measures that were agreed but the ones of most relevance to this inquiry were the decisions about the Home and Community Care program and also initiatives to reform the front end of aged care—the way people enter and receive information about services. In respect of the Home and Community Care program, all jurisdictions except at that time WA and Victoria—

Senator BOYCE—We are always the outlying states.

Mrs Smith—agreed that the Commonwealth would take responsibility for funding all HACC aged-care services for older people—that was non-Indigenous people aged 65 and over and Indigenous Australians aged 50 and over—and that was a really important step in terms of enabling the Commonwealth to develop a consistent aged-care system right through from basic home care through to high level residential care, and would also enable greater integration between aged care, acute care, primary care et cetera. Those directions were essentially confirmed by the COAG meeting last weekend. At that meeting all jurisdictions agreed that further reforms in aged care would be a priority over the next three years, but all parties agreed that the Commonwealth would be the level of government with full funding policy management and delivery responsibility for a national aged-care system, and all parties, excluding Victoria and WA, have agreed to the changes that had been previously agreed in relation to the Home and Community Care program. Victoria and Western Australia, though, have now agreed through the recent discussions on the weekend to a process of consultation with the Commonwealth and with local government stakeholders about considering potential changes in responsibilities for home and community care services. That is a consultation process that will take place over the next few months and be further considered at the next COAG meeting.

Obviously, though, as well as those significant reform processes under way, we also have the very significant Productivity Commission inquiry into care for older Australians. The commission released its draft report on Friday, 21 January. It is a very substantial piece of work.

Senator BOYCE—They always are.

Mrs Smith—And not only the report but the hundreds of pages of appendixes that I am sure we are all ploughing through with great interest. The Productivity Commission is going through a process of consultation on that report. It will be seeking public submissions and will be holding public hearings. The intention is that they would release their final report in June and obviously after that the government will need to consider its response. To sum up, we have a system which has a very rich array of current services, a big investment. We have our current reform agenda underway and we also have a long range process that will consider how we take the system through to the 20 or 30 years beyond.

CHAIR—A whole range of issues have come up during our hearings but one in particular at the very beginning has been—and it is a continuing issue—the assessment tool. The issue that is coming up frequently is people ageing with a disability and premature ageing and the fact that they are then not being picked up in the assessment tool. So what is being put to us—and you have seen the submissions and the *Hansard*—is that there should be changes to the assessment tool to take account of early onset ageing or premature ageing. Is that an issue that you have considered and looked at and how does the department handle that issue?

Mrs Mackey—Consideration of how we apply assessment across aged care is an ongoing issue for the department. In terms of comprehensive assessment through the aged-care assessment teams across the country there is not a prescribed assessment tool at this point in time. There are 108 different teams. They are all quite multidisciplinary and diverse teams, so based on clinical experience they employ different tools. Over the last 12 months the department has been supporting a piece of work, together with the states and territories, through a clinical reference group that was established to look at the range of assessment tools that were being used—the variability and reliability of them. We are now where that clinical reference group has come up with a very small number—three particular tools. I can find out further information about those tools for you. We are looking to roll them out as a more consistent approach over the next 12 to 18 months through the aged-care assessment teams.

Senator BOYCE—What will be the practical effect of that?

Mrs Mackey—Practically speaking in terms of national consistency we should see an increase in the consistency of assessments that are being applied, remembering though that one of the features of aged-care assessment teams is the fact that they are multidisciplinary and take that approach with individuals to look at their own circumstances rather than trying to fit them into particular criteria. So that is already one of the intents and objectives of doing the face-to-face comprehensive ACAT assessment and we would be keen to hear about particular examples where perhaps that ACAT assessment has not worked.

Your question goes to how many people under the age of 70 currently go through an ACAT assessment. The agreement that has been in place for a number of years now with the states and territories is that for a person with a disability seeking ACAT assessment is kind of the last point of call. It is where the state system is unable to provide the level of care and support that the person requires and therefore an ACAT assessment is required. The ACAT assessment should not be viewed as the assessment vehicle generally for access to disability support services in the state systems.

CHAIR—I take your point. What they are looking at, though, is access to aged-care support.

Mrs Smith—Was your question directed at people over 65 or under 65?

Senator BOYCE—Under 65 with a disability. Down syndrome is a classic example where you may have early onset dementia. What is the department’s view of what happens there now?

Mrs Mackey—The aged-care assessment teams screen a large number of people. We know that a large number of what we would call the non-target groups, so in the under 70 years assessment because that is the criterion at the moment in the ACAT space, 37 per cent of those do not go on to receive aged care.

Senator BOYCE—They don’t?

Mrs Mackey—They do not.

Senator BOYCE—Does that mean the rest do?

Mrs Mackey—They are assessed as ‘no care being recommended’ through that assessment process—in the aged-care context, not in the disability context. Twenty-six per cent of them are assessed as requiring HACC services. We would therefore say that the ACAT assessment was an inappropriate, or not the best course, to access those base-level services in the aged-care system.

CHAIR—So in terms of then being assessed for HACC, do they then go into the disability section of HACC under states?

Mrs Mackey—The way the aged-care system has been set up, the aged-care assessment teams do an assessment to determine the level of care that is required. That then is not a guarantee of a direct entry to that level of service provision. As you are both aware, there is a process by which that person can then take that assessment and they are given information about providers that may be able to provide that level of care, particularly because ACAT assessments are not designed as an assessment for HACC services. Because they are designed for community or residential care, that assessment is then referred on to a range of HACC service providers that may be able to cater to that person’s needs.

CHAIR—With the new process, with the states taking disabilities and the Commonwealth taking aged care, where do they then—

Senator BOYCE—If someone is so worried about your abilities to look after yourself that they have called in the ACAT team, and the answer is, ‘No, you are not aged care’, will something happen? Will something be done for those people?

Mrs Mackey—The first message is that when the Commonwealth commences taking full responsibility for aged care on 1 July with the HACC transition commencing, nothing changes with ACAT assessments. It will still be the case that people under the age of 70, or 65 as it will be, will be able to access an aged-care assessment through an ACAT. There are significant pieces of work between Commonwealth and state and territory officials to work out the administration arrangements that sit behind both that assessment process and the cross-billing arrangements for the ongoing delivery of services. So the important thing to refer back to is that we have a set of national guiding principles for the referral and assessment of younger people with a disability. They sit under the Aged Care Act—

Senator BOYCE—Young people with disabilities is anyone under 65. Is that it?

Mrs Mackey—Under 70 at the moment under the Aged Care Act and aged-care assessment teams—just to confuse things.

CHAIR—I hear ‘younger’ and I think you are dealing with really young people—for example, people transitioning from school into the brave new world.

Mrs Smith —Because we live in the aged-care space, 65 is pretty young.

CHAIR—I appreciate that, but the problem there is that we are talking about people prematurely ageing. We are talking about people in their 40s and 50s, so they are not young.

Ms Balmanno—I want to clarify something about the HACC split. There is a misconception of the way the split is going to work that we will regularly come across. From a service provider point of view and from a client point of view HACC is not splitting. The range of services that service providers currently provide and the range of clients they currently see will in most cases continue. What is changing is how their funding flows and what contributions the state and territory governments make to the funding. At the moment it is pooled funding on the basis of a proportional split, which is then delivering one program which meets the needs of a range of clients. It will be two separate funding programs tapping into the same service sector to meet the needs of two groups of clients. The Commonwealth will pay for the care of clients who are over 65, but it does not mean that the care they receive necessarily changes.

CHAIR—I hear what you are saying.

Ms Balmanno—The care they receive will be changed on the basis of the assessment of their needs and of what is available in a few different areas et cetera.

CHAIR—So here we are talking about people who have both their disability and early-onset aging, which causes a whole range of other issues. I am used to dealing with the states and the Commonwealth fighting about funding all the time.

Ms Balmanno—Those clients would still be able to access a range of services.

Senator BOYCE—But under state funded services.

Ms Balmanno—The state would fund. The services would be likely to be managed and delivered by the Commonwealth, but the states will be billed for the cost of clients under 65.

CHAIR—Even when the additional services that need to be provided are age related?

Ms Balmanno—Yes

CHAIR—So there is agreement from the states that even if they are age related but they are under 65 the states take responsibility.

Ms Balmanno—They take the bill, yes.

CHAIR—They take responsibility for the bill.

Ms Balmanno—Yes.

Mrs Mackey—Community care packages are quite a good example because we already have people who are under the age of 70, or 65 soon, accessing those packages. We have very good information about how long they stay on the packages and what their age cohorts are, and we are able to see them move through the system. Come 1 July, the states will become responsible for funding those packages that the Commonwealth now provides. Equally, the Commonwealth will become responsible for funding the disability services provided to people over the age of 65. The key tenet underpinning our entire decision making in terms of implementation is continuity of care. The administration arrangements are taking an enormous number of resources and amount of effort to work through. But we want to make sure that they do work and that they are not going to impact on the client. The client should see continuation of services and should continue to be able to access services just like they do now. If they are a new client coming into the system, they will not know any different. The existing pathways will be there.

CHAIR—I want to go back to the assessment tool. I think I was under the misconception that, when the changes to the ACAT team were brought more in line a couple of years ago, the rationalisation of the assessment tool had happened. I was under the impression that there was more commonality between the assessment tool earlier. However, having said that, they are now coming down to three. Is that correct?

Mrs Mackey—Yes

CHAIR—Where can we find them?

Mrs Mackey—I can get some information for you. Information has certainly been reported from that clinical reference group. We have networks of ACATs that are now working on what the next steps are in rolling out. We have some trials occurring. I can give you some information on those trials. We are working towards implementing more consistent approaches in assessment through the aged care assessment teams.

I should say that that is not the only work we are doing in assessment. For quite a number of years now the department has also been working on what we would call a ‘broad and shallow’ assessment tool—what screening or triage arrangement happens before someone needs a complex assessment. We have something which is called the ACNA.

Senator BOYCE—The what?

Mrs Mackey—It is another acronym. It is the aged care needs assessment—and the R is something.

Senator BOYCE—Record? Report?

Mrs Mackey—I will get you the correct term for the acronym. We have been trialling that tool over the past couple of years. We have built a support system around that and we have had it trialled in a number of states through their access points. There are eight access points operating across the country that are designed to streamline access to HACC services and provide base-level information around aged care. A number of those have trialled the ACNA tool for us, and we have had it evaluated. At the same time we have been developing another tool that is complementary. That is the CENA, which is the carers eligibility and needs assessment tool. What we want to do is have a tool for care recipients and their carers and we want to make sure we are considering both the carers’ needs and the care recipients’ needs as one.

Senator BOYCE—Can we have that tool as well?

Mrs Mackey—That tool has been developed. We have not gone to a trial phase because, as we were about to head into a trial phase, the COAG agreement last year presented to us an option to look at things in a slightly broader context, given the one-stop shop measure. We have now been considering the evidence we already have around this carer tool and how we would roll that out in a new or redesigned front-end for aged care.

CHAIR—You are going to provide us with the three assessment tools.

Senator BOYCE—And the carer assessment tool as well, if possible, please.

CHAIR—Going back to the initial question, which is whether people with a disability with early onset ageing get residential care or not, under the new assessment tools can that be picked up?

Senator BOYCE—Or that will be a state issue?

Mrs Mackey—The agreement that was established back in the late 1990s with the states and territories around people under the age of 70 accessing community care or residential care will remain in place. If it is agreed there are no other facilities or care services more appropriate to meet the person's needs then that is when an ACAT assessment is the most appropriate assessment and that is the pathway to community care or residential care.

Senator BOYCE—Where will someone in their forties with advanced dementia end up?

Mrs Mackey—They could end up receiving an extended aged care at home dementia package, EACH D—and we already have a number of people under the age of 70 receiving those packages—or they might end up in a residential facility if that is the most appropriate place for them to be.

Senator BOYCE—An aged-care facility?

Mrs Mackey—An aged-care residential facility.

Mrs Smith—That will remain an option—

Senator BOYCE—I should not have said 'where will they end up'; I meant: what choices will they be offered?

Mrs Smith—I suppose governments have long been trying to work with this area because it is usually not people's first preference. The key thing is to ensure that people are getting the care that is appropriate for their needs.

Senator BOYCE—We have had evidence about people working in disability enterprises who are not able to retire because there is no care available for them. They have to leave where they stay because they are only funded outside nine and three. They have to go to work irrespective of the fact that they are tired and do not want to work that way any longer. There is this big gap. They cannot retire when it would be physically and mentally appropriate for them to retire.

Mrs Mackey—I can provide you with information on those three assessment tools I was referring to. They are based on what you are trying to assess. The first component is around physical function. There are two assessment tools there: the first is the Modified Barthel Index and the second is the Older American Resources and Services Independent Activities Daily Living Tool. The second component is around cognitive function. The tool there is the Standard Mini-Mental State Examination.

Senator BOYCE—Would that vary depending on whether you already have a cognitive disability? Would that tool be used?

Mrs Mackey—My understanding with all of the tools is there are a set of generic questions or issues they tackle initially and, where there are certain triggers in those, they delve down more deeply into a person's ability and level of functionality.

Senator BOYCE—As I think you heard me ask FaHCSIA, there have been numerous submissions suggesting that the data that is available is patchy or not detailed enough and does not allow for specific focus on particular types of disability. Could you comment on the data in this area of people ageing with a disability?

Mrs Mackey—We certainly have quite good data about people with a disability who are accessing aged-care services before the age of 70—

Senator BOYCE—Before the age of 70?

Mrs Mackey—And certainly after.

Senator BOYCE—Can you characterise that group a bit then? Who are we talking about there?

Mrs Mackey—In community care we have quite good breakdowns by age cohort—by four-year age cohorts—the number of people receiving the type of package and how long they have been on that package, which gives us a fairly good indication of how people might expect to move through aged care and whether we are looking at a long-term or quite a short-term interaction. Certainly consistent with the ageing population across the country, you can see we have quite a significant number of people over the age of 50 who are accessing community care packages. We would expect them to need increasing levels of support through the aged-care system over the coming decade.

We equally have information through the aged care assessment teams. I would categorise that as not being quite as detailed in terms of what we have for the community care packages. We do have information that we collect through ACATs that identifies not only the age of the person but also the types of triggers for needing support and care assistance. We would not necessarily capture that a person had a particular disability, but we would certainly capture the limitations in terms of groupings of functionality or cognitive ability.

Senator BOYCE—FaHCSIA were telling us about some pilots they were doing to assist people to transition to use community facilities. Is there anything like that going on in the aged-care sector?

Mrs Mackey—The Department of Health and Ageing has a program through the National Respite for Carers Program. Around five per cent of people who access that program would be categorised as people with disabilities under the age of 65.

Senator BOYCE—So they are coming in for a few days or a week?

Mrs Mackey—There are a range of different service types within that program and that includes emergency respite to regular respite, and the respite could be overnight, in home or at a day therapy centre. It is quite individualised in terms of how that respite is delivered. That is quite a significant program that is delivered.

Senator BOYCE—Who actually delivers that program?

Mrs Mackey—It is delivered largely through our 54 Commonwealth respite and Carelink centres, so it is nationally available and geographically has quite a lot of coverage across the country.

Senator BOYCE—It has been raised that, in terms of using community facilities, there have been issues with integrating people, for want of a better word. Can you talk about how this is approached in aged-care facilities?

Mrs Mackey—Do you mean integrating—

Senator BOYCE—People with disabilities. I am now talking about people over 70 or 65—pick your figure—with disabilities moving into mainstream aged-care facilities.

Mrs Smith—I do not have specific information with me, but certainly under the accreditation requirements providers have an obligation to meet the care needs of all of their residents and they will have a range of residents with particular care needs that might be different from the mainstream, so to speak. I actually went to a facility in Melbourne yesterday that caters for homeless people and the age profile there was much younger than your typical age-care population. There were quite a lot of people who would fall into the under 65 category of people. They have a history of homelessness or are at risk of homelessness and have often got an acquired brain injury, particularly from alcohol consumption. It is a really interesting service in terms of how they cater for a particular group of residents.

Senator BOYCE—Are we talking about a few people in a mainstream aged-care facility or an aged-care facility specifically aimed at particular people?

Mrs Smith—I think we have a very diverse residential care sector, so we have a number of services that would be what you would call mainstream and care for a range of residents with differing care needs. We then have other services which tend to specialise more in particular types of care needs. To mention specific facilities, for example, as I have just described, some would specialise in homeless clients. There are 2,800 services across the country and we would probably need to take that on notice to give you a full picture. All providers are required to meet the care needs of the residents in their care.

Senator BOYCE—But that does not necessarily mean that residents who come from a mindset of people with disabilities being happiest separately are going to be nice to them, does it? What experience of that do you have?

Mrs Smith—I have had experience. Wearing my previous hat, I ran the Quality and Compliance Division before moving to this job. We would get representations from individual clients who were concerned that they should not be in an aged-care facility because they would prefer to be out in the community.

Senator BOYCE—That was younger people with disabilities?

Mrs Smith—We are battling a bit with this term ‘younger’.

Senator BOYCE—I am using under 65 just for the moment.

Mrs Smith—We have mechanisms through the complaints investigation scheme that the department runs for people who are concerned that a particular residential care service does not look after or respect their individual needs, to complain to and have that complaint dealt with in a fair way. We have the accreditation system which requires that they meet the care needs of residents, including those with special needs and I accept that people with a disability are a key group. But we also have people from non-English-speaking backgrounds and veterans who also have special needs and providers are very used to having to respond to those needs. I have not personally had a lot of complaints drawn to my attention from people with a disability who feel the service has not dealt with them appropriately.

Senator BOYCE—Nor are you likely to from people in their late 60s and 70s with an intellectual disability.

Mrs Smith—As I said, we have a complaints investigations scheme that has to cater for people with a variety of care needs and different levels of ability to prosecute their own cases. We get lots of complaints being made by family members, concerned staff and friends. Anyone who has a concern can raise a complaint, be it the person themselves or anyone who cares about that person.

CHAIR—We were discussing with FaHCSIA earlier that once you turn 65 you do not have to move on to an age pension—you can stay on DSP. If you then go through the ACAT assessment process and are then assessed as needing residential care but you remain on DSP, do you go in there with DSP or do you have to change over to the age pension?

Mrs Smith—I do not know.

Ms Balmanno—We will have to take it on notice.

CHAIR—Would the FaHCSIA people who have remained here know?

Dr Hartland—I think the answer to that question is no. Do we require you to change to age pension from DSP if you go in to aged care? I am very certain the answer is no.

Mrs Smith—From our point of view the proportion of income support that is required to be paid to that facility is very clear.

Dr Hartland—That is not related to the pension. There some other details in the rules about how the pension system interacts with aged care. There are some other quite complex provisions relating to how you treat the home that the person used to be in and that changes if they still have a partner living in the home. Again, I am very confident that that is not specific to the age pension but it may just be worth taking on notice. I am almost certain there is nothing in the income support system that would mean that it mattered whether you were on DSP or age pension when you are in residential aged care. I am very certain, but it is a complex system and there may be something small.

Mrs Smith—I believe that to be the case too, but we will take it on notice and get confirmation from our funding experts

CHAIR—It relates back to the issue we were talking about with you, Dr Hartland, about what other organisations or service providers put their eligibility criteria around what income support you are on.

Dr Hartland—Yes. We will double-check that. We are pretty confident. We would be very surprised if it mattered. There are differences between two systems that you might want to consider the choice, but I do not think it would relate to your funding.

CHAIR—We have had a number of representations from people who acquired a disability through polio. They have managed their disability, they are not on DSP. As they are getting older they are experiencing earlier onset ageing that is not related to dementia. But they are getting very significant issues now related to their former illness and they have raised concerns with us. There are a large number. Are they a particular group that have featured in discussions or have made representations to the department?

Mrs Smith—Not that I am aware.

CHAIR—Again it is associated with ageing so, for example, they are needing more supports and medications.

Mrs Smith—We are not aware of an issue but we would be happy to talk to people and inform ourselves of the particular issues they have. It has not come up as a big issue at this point.

CHAIR—The reason it came to the inquiry is that it is associated with ageing. They do not necessarily qualify for DSP but their conditions are associated with early onset ageing.

Mrs Smith—It has not been raised.

Senator BOYCE—It was also raised by the guy with cerebral palsy who gave evidence. He and his wife are ageing prematurely skeletally. That was the view he put to us. That has not been raised with you either?

Mrs Smith—No. But if people are experiencing those issues to the point that they need to access aged-care services they would be able to go through the assessment processes that we have just outlined.

CHAIR—All the processes we have just talked about?

Mrs Smith—Yes. The key issue is: if they have care needs that mean the only and best option would be for them to be cared for through aged-care services they can access them.

CHAIR—A lot of the issues that have been raised with us obviously relate to people’s understanding of the system. I know that you are addressing it and I know you have taken steps there.

Mrs Smith—We acknowledge that it is a complex system. The feedback you have received to your inquiry is consistent with what people have said to the Productivity Commission and elsewhere. This is a complex and difficult system to navigate at times. We have significant effort under way to actually improve the way people get information around how they are assessed, how they are referred. We also did a big round of consultations with people around the country prior to Christmas in terms of the work we are doing on one-stop-shops. It is also consistent with the feedback that has been provided in those sessions. People are comfortable that the initiatives we have under way are the ones they think are needed.

CHAIR—I want to go back to the issue of the ADEs. I do not think you touched on the interaction with the pilots that have been going on. I think you were here earlier when we were talking about the pilots with FaHCSIA. How involved are you in the pilots? I have just seen your head shake – are you not involved?

Mrs Smith—We are not involved.

Dr Hartland—It is probably remiss of us not to have more fully consulted with our colleagues in health but the pilots are focussed on community groups, so that is where we have gone first as a potential solution to this problem about mainstream community groups. We have not looked directly at aged care. We welcome their involvement in ADEs but the approach we have taken at the moment has been to look at how you might get mainstream community groups to accommodate these people who are retiring out of ADEs. We have not looked at the issue of whether aged care or related services would be the right answer. In many cases these people would already be tapped into state services like home and community care. That should be handled on the state side.

Ms Balmanno—Because we are not necessarily involved in the Commonwealth bureaucracy does not mean that aged care providers are not involved in this space. Particularly because of the nature of the HACC program where they are servicing the needs of younger and older people you would expect a number of them to have a strong interest in that kind of space.

CHAIR—I may be going back over grounds that Senator Boyce was touching on before which is this need for increased services. Because people are coming out of the ADE system there is a need for increased services. Remind me who picks that up? Does it go to HACC? For example they need more support. They cannot stay at home because at home there is no support between nine and three.

Senator BOYCE—It should be who picks this up so that they can stay at home. That would be the ultimate answer.

CHAIR—What I mean is that they cannot stay at home at present because there is nobody there to provide the support services they need. Where does that come in the funding?

Mrs Mackey—At the moment that is picked up partially in the HACC system, but more specifically through the National Respite for Carers Program. Before I was talking about when you have the 54—

Senator BOYCE—If they are in supported accommodation?

Mrs Mackey—If they are in supported accommodation they can still access the day respite and there is a number of respite groups that also happen. I talked about the 54 respite and care link centres that operate those. There are actually some 670 service providers through that program. It is a very large program that offers a full range of services. It is not specifically targeted at younger people with a disability.

Senator BOYCE—It is a young—

CHAIR—I find it so confusing. I am so pleased I am still young.

Mrs Mackey—Certainly that program was developed to target older people and support carers as they were supporting older people through the ageing process. Therefore the services are particularly targeted towards that grouping. However, we do work very closely with FaHCSIA.

CHAIR—Is this over 65? I am not trying to be difficult.

Mrs Mackey—With the National Respite for Carers Program, because there are a number of different service types within it, we do not exclude everyone under 65 from all of those programs. We can get you some written detail about that program that might be helpful. We can submit that. But we do work very closely with FaHCSIA in terms of the delivery of that program, particularly for younger carers and clients with mental health issues. There is crossover and work happening across both of the portfolios.

Senator BOYCE—You told us that you thought it was varied options of respite, but it is just respite—is that right?

Mrs Mackey—There are a number of services within the National Respite for Carers Program. The Commonwealth respite and Carelink centres themselves, as information assessment and referral points, are part of that program. There are all the different types of respite services. There are the day therapy centres. There is also the carer counselling support. There are the carer information support programs. I think it would be most helpful if we did give you some text around the program.

Senator BOYCE—Is this in fact a group that could assist parents for planning for when they are not around any more?

Mrs Mackey—I think for us one of the key points in the system is the Commonwealth respite and Carelink centres and they have been set up and designed to provide information and referral support to carers and care recipients. There is no age put on carers and care recipients in terms of that role that they play. It just so happens that the largest group that they support happen to be older people.

Senator BOYCE—You talked about them doing carer counselling, presumably something that does come up during carer counselling is, ‘What’s going to happen when I can no longer care?’

Mrs Mackey—The Carer Counselling Program is funded under the National Respite for Carers Program. We have a relationship with Carers Australia to deliver that program and Carers Australia delivers that program through the care associations in each state and territory. Some of those care associations are also Commonwealth respite and Carelink centres. Therefore the CRC is a delivery point for that counselling program. Not all 54 Commonwealth respite and Carelink centres provide that counselling program, but they can provide referrals to carers to access that program.

Mrs Smith—But I am assuming that the carers can talk about the range of issues that would be concerning them and that they need counselling—we are certainly well aware that—

Senator BOYCE—How would you pick up trends from that?

Mrs Mackey—We capture quite a lot of information and data through the Commonwealth respite and Carelink centres. Yesterday here in Canberra we had a day-long session with representatives from all 54 CRCCs. The biggest message they told us yesterday was how important it was to have a conversation with a carer and not just delve into what information is available because they need to have a full understanding. Most carers do not recognise for example that counselling might be a really positive support that they could access. So they do not ring up and say ‘I need counselling support’; they ring up and say ‘Here are my circumstances’. At the moment that program, and the way Commonwealth respite and Carelink centres respond to individuals approaching them, is to try and be as flexible as possible and understand as much as possible about what is available both state based but also in the region they are servicing. They have very good relationships with HACC service provides, very good relationships with aged care providers and equally across into the FaHCSIA space, some of the programs they offer.

CHAIR—A couple of issues for me there are, one, if the person retiring is living at home—and I am not having a go at the centres or the fact that that service is available—say they have been going five days a week and they are coming home permanently. It needs more than respite. To me that is a help but it is not the solution. Secondly, how much is the funding—we did get some numbers didn’t we. There are a lot of people that we are talking about here. Are the number of places there and that is all very well if you are living at home, but if you are in supportive accommodation what are the options available then?

Mrs Mackey—In the first instance we would say that the Commonwealth respite and Carelink centres are one option for people to access the information and to discuss and be provided with referral points. The work we have been doing around the delivery and development of a new front end for aged care since the COAG agreement in April last year has very much been with the state and territory governments. We have had many discussions with officials about the interactions between the disability and aged care front ends, you might say. Each state is on a slightly different pathway and taking a slightly different approach. However, all states have indicated a strong willingness to make sure that as much as possible there is an ease of access between the two systems. If you are making contact at one point, whether it be aged care or disability and in fact the other side can help you, we support people and refer them through to there. We are not just handing out a phone number and saying ‘This is the wrong place to enter the system.’ Some states are very keen to literally mirror what we do in aged care in the disability space so that it looks very, very similar for people. What was the second part of your question?

CHAIR—I appreciate that there has been extra funding for respite but I still get stories all the time of people saying, ‘I have to book three months ahead for respite.’ You know the stories as well as I do. How much funding is now available for respite and is it enough to support the number of people that we are talking about in an ageing environment, in ADEs?

Mrs Mackey—The way the current aged care system is set up is that we have a special program—the National Respite for Carers Program—and I am just getting the respite dollar figures now in that program. It is quite large. We also provide respite through all of the community care packages, so we have a component of respite in all of those. I do not have the figures here today to say what that component is.

CHAIR—It will not necessarily have a community care package though, will it?

Ms Balmanno—It is also through HACC services. Even if it is only a one-off service or a small number of regular services, HACC service is still available.

Mrs Smith—And then there is residential respite, obviously, as well.

CHAIR—Yes. With all those together, is there going to be enough in there to address this issue?

Mrs Smith—I am not sure I can offer an opinion on that.

Mrs Mackey—I think we could say that the HACC program has six per cent growth funds and those growth funds recognise the ageing population and the need to continue to grow service delivery. Respite is one of the service delivery elements of HACC. We would say that is one of the indications that the Commonwealth is continuing to try and meet the demand as it increases.

Mrs Smith—Clearly a major focus of the Productivity Commission inquiry is looking at what type of system and services we need to support the population we have going into the future, given our rapidly ageing population. We have a mechanism in terms of the long term planning. We have a number of current programs that have growth built into them. I think the broader question of system sustainability is one that the Productivity Commission has been tasked with.

CHAIR—We have a change of topic now.

Senator BOYCE—Yes. Again, submissions and anecdotal material—whilst the number of people moving into aged care, residential facilities with an adult child with a disability accompanying them is a small number, I suspect it is a growing number. What can the department tell me about that? What do you know about that?

Mrs Smith—We would have to take that on notice. I do not have any information. Would you just like numbers?

Senator BOYCE—No. I would like numbers if you have them but also some sort of an assessment of what this means—what, if anything, the department is doing around this issue. I would like to know whether you have any policies around it.

Mrs Smith—I am not aware of anything specific, but we will go back and talk to our colleagues and see what we can put together.

Senator BOYCE—This is generally worked out, I presume, by a negotiation between the individual facility and the family.

Mrs Smith—And it is potentially a very good option for that family, if that is what—

Senator BOYCE—It is often the best thing that is available. I am aware of a woman with a disability who continues to live at the same aged-care facility that she has lived at for over 40 years. She came in with her mother who has since died. This is absolutely her home and her world now. Whether there were originally some better options is a different question.

Mrs Smith—In fact, the service that I went to yesterday told me about a new facility they are setting up in Melbourne, which has funding from both aged care and disability, and the thinking is to enable those sorts of arrangements so that you could have a younger person with a disability and their ageing parent being able to reside together. I thought that was an interesting collaborative service model.

Senator BOYCE—Do you remember who that was who was doing that?

Mrs Smith—It was Wintringham, who have a homeless focus. They have formed a collaboration with a disability provider whose name I cannot remember, but I can get more detail for you. I thought it was an interesting service model. They are just opening up.

Senator BOYCE—But the department is not consciously involved in looking at this through models or anything else.

Mrs Smith—Not that I am aware of, but we can certainly see if there is anything relevant that we can provide.

CHAIR—We discussed where we have got to now out of COAG. WA and Victoria have now said they are going to go away and consult, as I understand it. What is the time frame for the changes now?

Ms Balmanno—Putting aside WA and Victoria?

CHAIR—Yes.

Ms Balmanno—Just to be clear, the time frame in relation to WA and Victoria is that it will be further considered, I think, with a view to trying to reach some sort of agreement on our way forward at the next COAG meeting. There is a clear milestone there, but we are not entirely clear what that milestone will deliver.

CHAIR—Is COAG in June?

Ms Balmanno—Mid-year. In terms of the rest of HACC, there are two key dates: 1 July this year and 1 July next year. So 1 July this year is when the Commonwealth takes full funding and policy responsibility for HACC services for people 65 and over, and 50 and over for Indigenous Australians. At the same time, the state takes funding and policy responsibility for people under those ages. From 1 July this year, for one year, the state will continue to deliver and be the program manger for both of those cohorts—so for both groups. For one transition year, the state will keep being the overall program manager for HACC. All that is really changing in this first year is the contributions into the HACC bucket, if you like. Currently, the Commonwealth puts in roughly 60 per cent and the states roughly 40 per cent. This is now being changed. It will be a roughly 70:30 split, but it will be explicitly based on the numbers of clients and the amount of service to those clients in the two age cohorts. So the contributions change; the program management arrangements and certainly the service delivery arrangements remain the same for the next year.

CHAIR—I want to be clear on that. There is a whole range of programs.

Ms Balmanno—Yes.

CHAIR—They are remaining the same until 1 July 2012?

Ms Balmanno—Yes, and the states continue as the program managers for that and there will be agreement between the Commonwealth and the state, a different but similar agreement to the one that exists now—about the funding contributions and the deliverables and the responsibilities et cetera.

CHAIR—So that arrangement is going to be developed between now and 1 July this year?

Ms Balmanno—Yes. But then 1 July next year, 2012, is when the operational transfer happens. So based on the same age split but from that point forwards the Commonwealth will be the program manager in relation to the funding of HACC services and the management of the HACC program for clients 65 and over and 50 and over for Indigenous Australians.

Mrs Smith—So it will not just be about dollars; it will be about us having the direct relationship with the service providers.

CHAIR—Okay, right.

Ms Balmanno—So from that point on we start to have a direct funding relationship with service providers.

CHAIR—So service providers will in effect then have two funding providers, state and Commonwealth.

Ms Balmanno—Yes. Many of these service providers already have multiple contracts with the state and multiple contracts with the Commonwealth.

CHAIR—Because they are doing community packages as well.

Mrs Smith—Yes.

CHAIR—And a range of the other things?

Ms Balmanno—Yes, but in terms of the HACC services, they will have two funding arrangements. We are certainly working with the state and territory governments now about what those funding arrangements will look like. So from a HACC provider point of view it is as simple as possible. As much as possible, we align our reporting expectations and those sorts of things so that it is produced once in relation to their HACC program and provided twice to the two funders. We are working with them to make sure we minimise the burden of having two arrangements on providers. We will obviously also start to have a direct role in relation to quality, compliance and complaints and the sorts of things that we would do as program managers as we do for the rest of aged care.

CHAIR—Do you envisage that it will be the same process that you currently use for residential care?

Ms Balmanno—To an extent. We are obviously looking at what elements of the processes for residential care should be applied and certainly the elements that apply to community packaged care and what from there should be applied to HACC. As you would understand, the role of a HACC provider in peoples’ lives is different from a community package care provider or a resi care. The level of responsibility that they take for caring for the client is different. It is a very different relationship with their provider who visit once a week or once a month.

CHAIR—You still get plenty of complaints though in terms of you are going into peoples homes, all of that.

Ms Balmanno—Yes and we are certainly very conscious that the whole purpose behind the transition in HACC and the movement of the aged care component of HACC to Commonwealth responsibility is to complete the platform, I guess, across aged care so that the Commonwealth can look towards the future around a more integrated model of aged care from basic care at home through to care in a residential facility. We are trying to align processes to those directions but we are also conscious that government has yet to take decisions on the shape of the longer term system that we are working towards. So we also want to maintain flexibility in our growth.

Mrs Smith—And this will be a carefully managed transition that ensures maximum service continuity for clients and we have given undertakings about keeping the program on its existing policy settings through a transition program. Over time of course, if the Commonwealth is responsible for the whole spectrum we will give thought to what is an appropriate framework that sits on top of that continuum but that would be done through the sorts of policy processes under way with the Productivity Commission. The key I think in this phase of transition for HACC is to ensure it is a very carefully managed transition that minimises impact on providers and ensures service continuity for clients.

Ms Balmanno—I will just mention, picking up on what Mrs Smith said, there is a third date in the COAG agreement from last year in relation to HACC and that is 1 July 2015. I guess it is an explicit statement by both the Commonwealth and state and territory governments not to make major changes to service delivery in the HACC space before that date. So we are basically allowing a one-year transition where the money changes but the program remains the same, and then a three-year transition where the operation and the management changes but where we try to maintain as much as possible of the way services are delivered as are currently in place—recognising there is a longer term reform agenda for aged care but the HACC sector needs time to move through the transition.

Mrs Mackey—It also recognises that there are already reforms under way in the HACC program that the Commonwealth and the states and territories are working on together.

Ms Balmanno—Common standards.

Mrs Mackey—The introduction of common standards is an example, but so is a wellness and an independence approach where the Commonwealth has been supporting states for a number of years in that regard as well.

Ms Balmanno—So those reforms will continue as part of current business, if you like.

CHAIR—So next year is not the end of the process?

Ms Balmanno—No, not at all.

CHAIR—I am looking at this transition process—the transition between disability and ageing, particularly for premature ageing. Bearing in mind the discussion we have just had, if they go over to HACC services they may then receive some services for disability and ageing?

Ms Balmanno—Yes.

CHAIR—If they are under 65 all of it will still be done by the state?

Ms Balmanno—Paid for by the state.

CHAIR—Paid for by the state. What about on age related?

Ms Balmanno—It would still be paid for by the state. They can be accessing aged care services but paid for by the state.

CHAIR—If I am a provider and I am under the brave new world of having to relate to the Commonwealth for aged care services and to the state, I may not be a provider for aged services under the Commonwealth but I am for the state. Is that correct?

Ms Balmanno—Ninety per cent of HACC providers do both. There is a small proportion at each end who are only disability providers and a small proportion who are only aged care providers. Ninety per cent are—

CHAIR—But I did not get the tender from you.

Ms Balmanno—We are not tender agents.

CHAIR—Right.

Ms Balmanno—The intention is that if they are a current provider they will continue to be a provider. Clearly it is not an ironclad guarantee because some service providers may have organisational issues and we cannot in good faith fund them, for example. The intention is to maintain the mix of providers, to recognise that there are roles for state governments, local governments, non government private providers in the HACC space and that that will continue to be the case until at least 2015; and to recognise that there is a role for small providers, large providers—a whole range. We would expect to see that continue.

CHAIR—Okay. So we are not throwing all the tendering process up in the air?

Ms Balmanno—There is no tender process for HACC.

CHAIR—Okay.

Ms Balmanno—What government may choose to do after the Productivity Commission report in terms of the longer term reforms is obviously an unknown. In terms of the current policy decisions, the current implementation of those, there is no tender process for HACC.

CHAIR—Okay, and of course you put in your tender process—

Ms Balmanno—When I say 'tender' I mean non competitive.

CHAIR—Yes, not a competitive process.

Ms Balmanno—Using the word 'tender' in the broad sense.

CHAIR— Will the process for the community care packages remain the same?

Mrs Mackey—It is unchanged so clearly care packages are through the ACAR rounds, except for consumer directed care which we do separately at this point of time.

CHAIR—Quite a lot of providers do both.

Mrs Mackey—That is right.

CHAIR—So they will still go through the normal process for allocation of community care?

Mrs Mackey—That is right. There are very few of our community care package providers who are not HACC providers as well.

Mrs Smith—As we said before, it is a really carefully managed transition to manage the risks and ensure that service delivery continues, providers have minimal impact, particularly clients have minimal impact. We have given a commitment to 2015 that existing service delivery arrangements will continue but we do have a major Productivity Commission inquiry. Depending on what decisions the government makes as a result of that, there would also need to be a carefully managed transition plan. The Productivity Commission has recommended in its draft report a five-year transition to get to where they see the world should go. I think everyone would be very mindful of the risks of rapid change in an area that delivers services for very vulnerable people.

Ms Balmanno—Can I just clarify a point. When I say there will be no competitive process for HACC, that is in relation to the base HACC funding—the existing funding. As mentioned earlier, there is growth funding available each year to expand HACC services. At present, that funding is allocated through a mixture of direct allocation based on needs based planning in some states and some elements of competitive tendering, a competitive application process from providers for growth funding, expansion and new services. While we have not decided the final model of how that growth funding will be managed from 2012-13 and beyond by the Commonwealth, it seems likely that we would pick up some of the elements of what the states are doing and there could very well be a competitive element to some of that growth money.

CHAIR—For the growth funding.

Ms Balmanno—Yes. But that is not indexation of their existing funding. That would be rolled through the—

CHAIR—This is where you have done the additional allocation.

Ms Balmanno—We would expect there to be some competition in that space, balanced with some regional planning and needs assessment, looking at where the pressures are in the system.

CHAIR—That is the clearest explanation I have had to date of where we are at with HACC, so thank you.

Senator BOYCE—You have explained how you are managing this transition very carefully to try to make sure that no-one falls through the cracks or gets left behind or whatever. Could we talk somewhat more generally about what is available in this space, and has been in the past, between disability and ageing and talk about what other safeguards you have in place for trying to make sure that people do not fall through the cracks, and what audits you have done in this area?

Ms Balmanno—I guess it is a tricky question to answer because at the moment it is not two separate spaces, from our point of view.

Senator BOYCE—But disability has been state and—

Ms Balmanno—It has not, in that we are joint funders of the HACC program.

Senator BOYCE—But that is not all that happens in—

Ms Balmanno—No, but I am saying that from our perspective—

Senator BOYCE—From your perspective it is.

Ms Balmanno—at the moment we are part of the disability space. As Mrs Mackey mentioned in relation to the National Respite for Carers Program and others, I think we are moving to a situation where there will be more of a line between Commonwealth and state roles but still not a strict line. The Commonwealth will continue to have interests, including in-service delivery to people with a disability, through FaHCSIA and through the carers program respite services.

Senator BOYCE—We have had enough people already telling us it is complicated and that they cannot work out what is going on or what is happening. What might some of these submitters take out of this to attempt to reassure them it is going to get simpler?

Mrs Mackey—I think the first thing to take out is that, based on the COAG reforms agreed to in April last year, we have commenced a process of developing a new front end for aged care. The front end, even though it is for aged care, is actually for over-65s, so that front end will be able to help and assist people to access the services they need after going through an assessment process. Sometimes that assessment process will be quite a deep and complex assessment process and at other times it will be a broad and shallow assessment process. That is the first thing.

Senator BOYCE—That is the point. People do not sit down and think, ‘Ah, I’m 64½, I won’t need a broad and shallow process.’ They want seamless delivery from 30 or whatever—pick a figure.

Mrs Mackey—That is why the work we have been doing with the states and territories to look at how we make the two systems complementary to each other and that there is not seen to be this wall between them is a really important element of the work we are doing to implement the new front end. For example, the Northern Territory has already embarked on developing essentially a one-stop shop for disability. It is based in Darwin. They have done quite a bit of work around—

Senator BOYCE—Is that for over-65s with a disability?

Mrs Mackey—It is for anyone with a disability. They already acknowledge that, in people’s minds, there is not a clear delineation of how old they are and whether they should have an ACAT assessment. There are already strong links between the one-stop shop they have put in place and the ACAT assessment team. The Northern Territory is a little bit easier for us to think about because they essentially only have a couple of ACAT teams. They do not have the large numbers that the other states do and their ACAT team services the whole top half of the NT. So there are very strong linkages between that disability front end and the ACAT team to try to make sure we have the right supports in place for the individual. We are not drawing strong lines around things; we are trying to look at how we build collaboration and partnership between the two areas.

Senator BOYCE—And how you guard those, too.

Mrs Smith—We are working closely with states and territories. There are detailed discussions occurring. They have been coming to the consultation sessions that have been occurring around the HACC transition and reforming the front end. There is some really good collaboration going on. We have a group called aged and community care officials which is a forum for us to get together with state and territory officials as well as our bilateral discussions. I think FaHCSIA have told you they have a similar group in the disability space. We have committed to have a joint meeting in mid March to ensure that exactly this sort of discussion continues, because we want the system to work for people. It is a complex system, we acknowledge that, but I think the work that we have got underway is of interest to our state colleagues in terms of the services they will be responsible for as well and how we can get the two systems working together.

Senator BOYCE—I just want one clarification on the one-stop shop for disability in the Northern Territory. I took out of that that the Northern Territory government is funding and driving that. Is that correct or not?

Mrs Mackey—That is correct. I do not think the name of it is actually ‘one-stop shop’; I cannot quite recall what they have called it.

CHAIR—We have just called up a media release that announced the launching of it. They called it in the media release a ‘One-stop-shop for Disability Services’.

Ms Balmanno—That sounds right.

CHAIR—Just so you know, we are going to write to them and ask them how it is going. I will ‘stop while we are ahead’ although we are actually a couple of minutes late. Thank you. It is very much appreciated. It has really helped to clarify where we are at with all these services and supports. Also, thank you to Ms Bedford and Dr Hartland for staying behind and helping. That is very much appreciated.

Proceedings suspended from 1.15 pm to 2.24 pm

ALBERT, Mr Stephen Michael, West Kimberley Member, Western Australian Aboriginal Education and Training Council

Evidence was taken via teleconference—

CHAIR—I would like to welcome you, Mr Albert, in your capacity as representative of the Western Australian Aboriginal Education and Training Council. Did you get information on parliamentary privilege and the protection of witnesses in regard to the evidence that you are about to give?

Mr Albert—Yes, I just read it in my email the other day.

CHAIR—Okay, fantastic. We just wanted to double check that you had got it. I invite you make an opening statement and then we will ask you some questions.

Mr Albert—When it comes to the education and training of our people who have disabilities you find that if you look at the five disciplines—early childhood, primary, secondary, adult or TAFE education, and tertiary—in many instances nobody is aware of what services or programs are available.

There needs to be a lot of advocacy for both the client and the service provider in putting up programs for our people. I have a disability; I am an amputee. My interest is in this area, although I have been involved in education for over 30 years. There needs to be an awareness by the service delivery agencies. It hurts me when a government officer, an education officer, a teacher or a principal says, ‘We do not discriminate; we treat all our students the same.’ That person is stupid or arrogant or lazy. Those sorts of things need to be looked at so that there are proper programs available or programs that can be pushed for people with disabilities. As you know, people come in all forms. They could be blind or deaf. They could be autistic or bipolar—all sorts. Schools and institutions need to recognise these people.

The other thing which has come up in more recent times and which will impact our kids in future generations is the alcohol foetal syndrome. I do not have any answers there. I am just making a general statement to put you in the picture about the stuff I am looking at when I travel, when I make my community visits and when I talk to people.

CHAIR—Thank you. Is that all?

Mr Albert—That is a general statement. Then, if you look at our submissions, you will see that we need some more consultation and you will see that we need Aboriginal communities and family members to be involved. We also state that some of the services are not available to people. It differs. You have people who live in the urban areas, people in the non-urban areas and people living in the country—either rural or isolated. Then, of course, we have a mix of our people who are traditional people and some of our people who are more sophisticated in the westernised lifestyle. So some people are able to access services that are available but others are not so lucky. So we are asking: how do we go out to people and get the message across or assist them in getting them to do programs? Somewhere along the line people need to come and visit these places, so there has to be a lot more advocacy done by Indigenous people to bring the two things—the service delivery and the clients—together.

Also, people with disabilities need to be included in our society. If they are not included we need to make things available so that they are able to be part of the community. Otherwise, if you get treated like a leper, or if you do not get treated at all, you are in one part of society that is just not keeping up with everything else. If you waste more money spending on programs that do not work and it is no good for you, it is no good for the government and it is no good for us. Somewhere along the line we need to sort things out.

CHAIR—Thank you.

Senator BOYCE—Mr Albert, could you describe for us a little bit about what life is like for the ageing parents or carers of someone with a disability living in a remote Aboriginal community?

Mr Albert—Okay. I will do it one at a time. If we look at an ageing carer who is looking after somebody with a disability—a young person—then that ageing carer will spend most of his or her time trying to make sure that the child gets a good education or good training, or ensuring somehow that she or he performs in a way that is part of the community and is not seen as an eyesore or whatever, so that they are able to join in the activities of the other kids. Or, if there is an adult education program, the carer will spend time making sure that the child is able to do a training course at TAFE or an apprenticeship. But sometimes the carers get burnt out. In my Kimberley experience, we do not have enough respite areas where people can go. There are a couple of places in Broome where people can come to good accommodation where they have got their own room and they can move around in a wheelchair or have their carers with them. They can spend a bit of good times just shopping or whatever, or even have a bit of a holiday.

But carers who are out in the bush, if they are lucky and know the information, are able to try to go to this place of respite. I know that once a year in the Kimberley they try to get carers together and they might go to Kununurra for a big workshop where they can relax and work out how they can be better carers, or they might do one in the West Kimberley or somewhere in Fitzroy. Those things are happening but they are only once a year, sort of thing. The everyday thing about carers is that they do it themselves.

It is a good thing our family unit in Indigenous society is probably much better than in the non-Indigenous society, because we have got the extended family with cousins and so on. So it does not affect one person in the family; it affects the whole family unit. But the other thing is the reverse role. If you are a young person who is caring for your granny, your aunty or your uncle, sometimes your education and training could be hindered because you are using your time looking after your family. So then you look at education and training. Can you see the two things?

Senator BOYCE—Yes, absolutely. We had evidence from the Mental Health Council of Australia talking about children as young as nine caring for parents generally—family members with a mental health problem—and deciding that they could not possibly go to university because it was not something they could do. Is that the sort of thing you are talking about there?

Mr Albert—That is the kind of thing there. That is for the ones who are going to the university. But if you go to the younger ones they are missing out on their grades in school. You can have a 14-year-old looking after their family and they are only up to grade 3 standard. Then what happens is that they become a disability.

Senator BOYCE—That is right. You have talked about the strength of the family unit. Could you talk about what happens—and I know this is in general—when an ageing parent or carer can no longer care for the child or the person with a disability?

Mr Albert—Mostly what happens is that, if they do not get help or assistance from their immediate family, we get our health workers within the community and they are able to get their attention. If they have their family record and all that it can be controlled or people can do something about it. But if you do not have any records of that sort of stuff—because the carer is getting old and because nobody has thought about it—it can be very, very difficult.

Senator BOYCE—What sorts of records should there be?

Mr Albert—With any person, especially a patient, there should be a health record—their track record on how they are going. I think that should be for everyone. With today’s technology you should be able to hit a button and know about that person. Take me for instance. I have been in car accidents, I have been in a plane crash. I have had a quadruple bypass. I got my leg chopped off. I am a diabetic. Broome Regional Aboriginal Medical Service will have my record so if I am half dead in Melbourne all they will have to do is press a button to see my health record.

Senator BOYCE—Yes, so that would mean that a ‘stranger’—for want of a better word—would have some background on how to care for you.

Mr Albert—Yes, and then you would know the history of the person. But I do not think that sort of stuff has been done yet. And that is the kind of thing that could be easily done by keeping records of people. I do not mean to say you use a Big Brother thing but it is a sort of a caring thing. You know that if somebody is 70 and she has been caring for a husband who is probably 60 or maybe 80, those two people somewhere along the line are going to peg out. In the meantime is the health worker, somebody else or the family already anticipating? Nobody follows up that sort of stuff. I am not too sure whose responsibility it is to help these people.

Senator BOYCE—I think the reason for the inquiry is that no-one is quite sure whose responsibility that is. So what would happen right now is that it would either be the extended family or a health worker who would think about the need to say, ‘Hey, Harry is getting lots older, we need to start thinking about this.’

Mr Albert—Yes, it would be the community health worker or, if it is a community where they have a local council, they should be aware of that. Somebody should let them know this is happening or the family should, somewhere along the line. That kind of network is hazy. It is like a maze. You do not know where to go to get that sort of assistance.

Senator BOYCE—We had evidence from the CEO of a peak intellectual disability group saying he did not understand all the services and programs that were available for disability so I think the rest of us are excused. That was basically his full-time job and he still did not understand it. You mentioned foetal alcohol spectrum disorder earlier. Could you just tell us what the specific problems are in this area around planning for the future?

Mr Albert—I am highlighting it because it is going to be a problem. I know it is going to happen. At this stage our teachers do not get in their teacher training about how to recognise those symptoms within a child. Then you have confidentiality things so you cannot just go to a child or their parents and say to the parents, ‘I think your child has this or that.’ There has to be a go-between and usually it will be somebody from the school. You need to have that Aboriginal person who is able to go between the teacher and the parent and try and discuss that so there is no conflict between the people involved. That makes it a bit easier. What happens is that the particular child might be in school and get suspended for the wrong reasons.

Senator BOYCE—For challenging behaviours—

Mr Albert—Yes.

Senator BOYCE—because people do not understand what is causing the behaviour?

Mr Albert—Yes. So what happens is that you have that behavioural stuff in school. For instance, I come from Broome and Broome is supposed to be the most sophisticated town in the Kimberley, right?

Senator BOYCE—Absolutely.

CHAIR—I am a West Australian, as you probably know.

Senator BOYCE—And I am a Queenslander but I will agree with that too.

Mr Albert—Yes, but how come we have 90 kids who do not go to school because they have been suspended? We have over 90 kids who do not even go to school at all.

CHAIR—In other words, we are not handling this issue properly.

Mr Albert—Yes, so we do not know whether the bad behaviour of those kids is because they are bad or because they have other syndromes.

Senator BOYCE—Or some other reason, like autism, or whatever.

Mr Albert—Yes.

Senator BOYCE—Presumably if their behaviour is such that they are getting suspended from school their parents would be having more difficulty caring for them as well. Would that be the case?

Mr Albert—Yes, that would be the case and, as somebody in education, I can say that somehow we need to try and get those kids to come back to school and make them interested in school—to let the students know that school is a very important thing for their life. They need to go to school because it is very important. They should not see school as a bad thing. So you need to overcome that. Sometimes we might have to look for alternative style education.

CHAIR—So do you modify the approach to education for these kids so that we are meeting their needs, addressing behavioural problems et cetera?

Mr Albert—Yes, I think for kids with disabilities—whether because of a limb or deaf culture or some sort of thing that hinders them from tackling the school in a normal situation—it needs to be recognised that you may even need what I call a positive discrimination, like a classroom made for them. But you do not have a different school.

Senator BOYCE—No.

Mr Albert—Because they have to be included with the rest of the school.

CHAIR—Yes.

Mr Albert—You have specialised teachers.

Senator BOYCE—Or at least someone there who can teach the other teachers how to deal with some of those issues.

Mr Albert—Yes, and you have the teachers who are able to combine their skills to be able to teach. They have to be more patient; they need to be a little bit more tolerant. Take it this way, if you have a speech problem and stutter all the time, it is best to let the bloke stutter and finish his sentence rather than jumping in and finishing it for him.

Senator BOYCE—Absolutely.

Mr Albert—That is the sort thing a teacher needs to know about—not to jump in but to let the person work for it, which is going to get him there. I have not been to teacher training because I am not a teacher. I have not had a look at the teacher training program, but that is one thing that I would like to have a look at. If you look at our history, you will talk about the kids from the 1950s, the kids from the 1970s et cetera. Now you have young people in the new millennium. Evolution happens, so I think the training of teachers should be evolving at the same time. They need to learn special skills so they are able to teach properly.

That is part of it. What should also have more Indigenous people involved, as part of the teaching staff or as mentors. Up in Broome, I have got people who have disabilities. They might not have a leg or an arm or whatever, but their mind is pretty good. They have been workers. I like to get them in to talk to the young people and tell stories about how they worked and got on with things. A lot of our people going through education and training today are probably fourth generation nonworkers. So they do not know how to work to get pay.

Senator BOYCE—So you have to learn to work for a wage.

Mr Albert—They do not have that working ethic. Nobody has told them, and that has been for four generations. They do not know what to do.

You get elders talking and saying—‘It’s like in the Kimberleys when they put sheep up there; they never should have done in the first place.’ The old Aboriginal people, the women and all, used to shear the wool, wash it in the river, put it in bales and then truck it down to Derby or somewhere. That was work for them, sun-up to sundown, and all they got was bread and tea, until the award wages came through. Those sorts of things should be taught in schools, to tell our kids, ‘You haven’t got it tough; the older people have done it before. They’ve been really good people. They’ve never been bludgers. They haven’t been nonworkers.’

Senator BOYCE—I am not sure that any generation believes that they are not worse off than the one before! Just getting back to the general issue of disability, could you talk a little about the level of stigma attached to disability in rural and remote Aboriginal communities?

Mr Albert—I can only talk about the region that I am in. We try and promote people with disabilities who are really good. Yesterday we had Try-a-Trade with the National Disability Office. I went to all the schools in the East Kimberley, West Kimberley and East Pilbara and took tradespeople with me. A couple of them were Aboriginal people in wheelchairs—one was a painter and the other one was a filmmaker. It was just to show all the kids, whether they have a disability or not, that they can do things.

Senator BOYCE—What sort of comments did you get?

Mr Albert—The schools love it. That is why I am trying to get some funds to do it again, to go out to the kids. Then they can feel that people are capable of doing anything, that they are normal people. It does not matter that they look a little bit different.

When people with disabilities go to the communities, because they do not have sealed roads—some have sealed roads now, but you have probably heard the story before of overcrowding and everything else—wheelchairs break down. No sooner do people get them than they break down, and there is nobody there to repair them. There are those little things like that.

Senator BOYCE—The practical side of it.

Mr Albert—The practical side of things happen there. But the thing that is missing is that there are not enough people going out and talking to the community and saying to them: ‘Yes, we do have people with disabilities,’ and, ‘Yes, we are trying to have programs to make them feel part of the community,’ and ‘Yes, there are services that are paid for by the government so you can go from one place to another to better yourself.’ This is where the lack of communication is happening.

Sometimes when you go to some of the offices you can see they are quite comfortable to sit in the office and get a pay cheque every day and all that. Yet, when you put on a fundraiser—you get the band, you do the fundraiser and all that—the same guys who are working for the disability mob do not even turn up. You think to yourself, ‘What the hell are they working in there for?’ All they care about is just getting their money and taking it home. After five o’clock they have finished.

I look at things both ways. I look at the person who works in disability who is delivering the service and I also think of what commitment they have, even if they have extra-curricular activities after work. That is why I think the missionaries in the old days were better than all our education that we have today. I mean, even though they had a missionary life and whatever, some places were bad but other places were really good.

Senator BOYCE—Yes, their level of commitment was always high. There might be some other aspects of it that you might not think are so good. We have had evidence from a broad group of people concerned about the potential for people with disabilities to end up homeless, or with no-one caring about them if their parents or their main carers die or cannot care for them anymore. Has that happened in your experience in communities around Broome?

Mr Albert—Not that I have heard of but I can imagine it can. In the Kimberley situation we have, say, a major town like Broome, and then you might have another community like Bidyadanga or Beagle Bay, which is another community. Then you might have what you might call a homeland, or an outstation, and you will find from the homeland and the outstation that the caring situation is much better than when you go to the bigger settlement and then when you go to a bigger town.

Senator BOYCE—Because everyone knows everybody and cares about everybody.

Mr Albert—Everybody knows everybody, yes.

CHAIR—And they are around all the time.

Mr Albert—And they are around all the time. If you look at the demography of Aboriginal people, there are people who live in the home group or family group, then you have people who live in the community which is maybe a settlement or a mission, and then you have people who live in the town or an urban situation such as a regional town like Broome or Derby, and then you have people who live in the city. The people who live in the city could have a group of people together or they could be dispersed Aboriginal people, so you do not get them.

If you are a city dweller who is disabled and you are one of those people who are dispersed, then if you do not have contact with anybody you can be dead within the city much more easily than out in the country. So there is a different situation for the different places. Because we are an education and training council, we try and cater for the different categories that we have. I concentrate on the region of West Kimberley. Have in mind that have we three different systems—the government system, the Catholic system and the Aboriginal independent schools—and they come from different communities there. If we know the population of people with a disability then we are able to deliver the service much better. One of the things that I have been trying to get the department to find out is how many people—not only Indigenous people but also other people—have a disability and how we can service them. But I do not have the numbers. I have got a little club that is called GOOYAAL, which means ‘Get Out Of Your Abode And Live’.

Mr Albert—What we would like to do is set up a hydropool up there in Broome so that we do not have to go down to Perth all the time or go elsewhere. If we have it there in Broome people from out of town can come there. People with a disability need to be fit because you need to exercise your joints and you need your blood flow and all of that to be working. You need to go to the gym and do that sort of stuff, so a hydropool would be good. But the other thing about equipment when you are talking about schools—it is the same thing again—is that every other kid has their basketball court, their football oval and all that sort of stuff, but the kids with a disability do not have that stuff, such as equipment. They need press-ups and other gym stuff so they can develop their muscles and get their joints going. This is besides their school work. They need to keep fit as well. There is no vote in the education system to buy this equipment. We have to do fund-raising to try and get money for that equipment, and I find that despairing.

CHAIR—When you said that you have tried to get information about the numbers, is it the case that the department cannot give them to you or will not give them to you?

Mr Albert—Because of confidentiality you cannot get much information. However, you can probably get the information from the census and you might also, if some of the kids go on secondary grants or study grants, get the information from Centrelink. But trying to get access to that kind of information is hard.

Senator BOYCE—You want that so you can plan, basically.

Mr Albert—So we can plan ahead. You get some of our young people who suddenly acquire a disability but they are pretty smart and they could probably go straight through to university or become somebody. But we do not have anything in place where we can assist such people. We have got footballers, we have got other things like AIS and all the other stuff, but we do not have anything for our mob to be able to give them a career path.

Senator BOYCE—We have Senate estimates next week, Mr Albert; we can try and follow up with some queries about how we might get some good data, as a starting point at least.

CHAIR—And see how that can be made available to community based organisations for the work they do and to help to plan for people with disabilities in their communities.

Mr Albert—I would like to end with the fact that there needs to be a lot of advocacy done by Indigenous people themselves on disability. Our own people, especially our people with disabilities, need to go out there and say: ‘Here we are. We can do anything we want to do. We are putting our hand up. We do not want a handout. We are putting our hand up. Here we are. What are you guys going to do for us?’

CHAIR—Thank you, Mr Albert. I understand you are in Victoria so thank you for taking time out to speak to us; it is very much appreciated. It brings a really important issue to the attention of the committee.

Mr Albert—Thank you very much for the invitation. I can promise you this: if ever you come up to Broome I can take you on a tour and all that sort of stuff in the Kimberley. I can bring you guys around, no worries. You have got your own tour guide here.

Senator BOYCE—Senator Siewert is forever trying to get us to Western Australia, Mr Albert, so we will certainly be trying.

Mr Albert—Good one! Thank you.

[3.02 pm]

CHALMERS, Dr Ron, Director General, Disability Services Commission, Western Australia

Evidence was taken via teleconference—

CHAIR—Welcome and thank you for joining us, Dr Chalmers, from the great city of Perth. I understand that you have had information on parliamentary privilege and the protection of witnesses and evidence provided to you.

Dr Chalmers—That is correct.

CHAIR—We have your submission, which is No. 11. I would like to invite you to make an opening statement and then we will ask you some questions. I am sure you know the pack drill.

Dr Chalmers—For sure. I will keep the intro fairly short. I think the submission not only captures fairly well the issues and the challenges that we face here in WA but also attempts to outline what we are doing about those issues and challenges as well. There are a couple of contextual issues, though, that might be relevant to this agenda and which might explain a little bit about how we are a bit different here in WA than other states and territories.

CHAIR—I keep telling people that here.

Senator BOYCE—And we Queenslanders wonder if this is a positive thing, Dr Chalmers!

Dr Chalmers—Oh, goodness! I will tread carefully. We have been on a bit of a journey for the past two decades on a number of fronts. Firstly, we are highly individualised in our response to people’s needs, to the point where well over 85 per cent of all of our funding—funding from the state government as well as the mix of Commonwealth dollars—is directed to individuals rather than in block grants to service providers. We have a state government that wants us to go even further down that path of individualised, personalised, self-directed services, and we are gearing up for doing just that.

We also have a very strong and diverse non-government sector, with over 65 per cent of our services provided from non-government agencies. We are working very hard to expand that sector even further so that it can provide even more choice and flexibility for people of all ages, including people who are ageing, so they can get the supports that they want rather than what government or the service providers think they need. That is just a bit of contextual stuff.

I will be cheeky here and say I did overhear a bit of your early chat there about LACs,—maybe a bit depends on the quality of the LACs. We have been working for 22 years now to build our local area coordination network, which is now recognised as being pretty cutting-edge right around the world. It is being rolled out in other parts of the world. We rely very heavily on that local area coordination network to assist in the planning that is required around people of all ages—young families, people leaving school and people leaving work at the end of their working lives—including individualised planning around people who are ageing and ageing carers. We will continue to grow that service into the future to meet people’s needs. You also have in the paper—and I will not go to each one of them—some of the other initiatives that are fairly new here in the west that also assist people to plan for and gear up for the supports that they need to meet their particular requirements. I am happy to answer any questions about those.

I will conclude by saying we have invested very heavily over the past half decade or so in the business of planning, and we think we have built the skill base of not only our own people but also the non-government sector and families themselves to plan better to meet the needs of family members who are ageing and ageing carers. One caution is that—and we continually remind ourselves of this—you can do an awful lot of planning but, unless you do the doing at the end of the planning, then the planning comes to nought. I might leave it at that.

Senator BOYCE—I suggest that perhaps part of the problem with the doing, in a national context anyway, is the inability of families to identify people to do it with—organisations, services et cetera. The gaps in the systems are often so wide that people are just daunted by the prospect of what to do next.

Dr Chalmers—There is certainly an element of that. Another way of looking at that is that an obvious gap exists between the need and the resources that are available. You can cut that any way you like—if there is a significant gap between need and resources, we are into that problem.

CHAIR—I am pretty certain you have the *Hansard* from our hearing in November when we heard from the Daintons.

Dr Chalmers—Yes, and I am very familiar with them. I have known Mr Dainton for about 15 years directly so I know what is going on there.

CHAIR—I gathered from the evidence that we received before—both the submission and the oral evidence—that you obviously did. We said to the Daintons we would follow it up, so we are interested in hearing your response, but I also want to then go on to the broader issue of the microboards and how that is developing in Western Australia, if that is okay with you.

Dr Chalmers—Sure, that is absolutely fine.

CHAIR—Could you tell us where you think the commission is up to with the Daintons? I hate to say that things have broken down, but where are things not connecting?

Dr Chalmers—Maybe I just need to ask a question before I launch into an answer. I always get a bit nervous when I start to talk about individuals and personal circumstances. In what sort of form will that appear in any report out of this inquiry? Will it be personalised like that?

Senator BOYCE—It will appear as it is spoken.

CHAIR—It is basically a verbatim record of what you say. Although we could take in camera evidence if you feel more comfortable doing that.

Dr Chalmers—I think I would feel more comfortable simply because what I have to say is very much focused on that family’s circumstances.

CHAIR—If you would feel more comfortable if we went in camera I just need to seek a bit of advice that we can do that virtually straight away. We will take your evidence but it will be in camera which means it will not be on publicly released *Hansard* unless we as a committee feel that we need to refer to it in our report, and then we would come back to you and talk to you about that anyway.

Senator BOYCE—And to the Daintons, too.

CHAIR—And to the Daintons as well.

Senator BOYCE—Dr Chalmers, the Daintons have been extremely open with us and with all the material they have given us about their circumstances. Even the financial aspects are now on the record.

Dr Chalmers—Okay.

CHAIR—We can go in camera now. If you would prefer to do that, we can do that and then come back to you about any possible release of the evidence.

Dr Chalmers—I am very happy with that.

Evidence was then taken in camera but later resumed in public—

Proceedings suspended from 3.12 pm to 3.26 pm

Senator BOYCE—My question relates to some of the conversation we have been having, Dr Chalmers. What requirements does the commission have around the structure of a microboard that would meet any concerns you might have about monitoring and governance?

Dr Chalmers—Vela Microboards is still a relatively new concept over here in the west, so we do not have hundreds and hundreds of people using that mechanism. We have funded Perth Home Care and other groups to really explore the flexibility that we can build into the whole microboard concept.

Senator BOYCE—Home Care being a service provider?

Dr Chalmers—Yes, but they have effectively built a bit of an arm on their organisation that focuses on this notion of Vela Microboards.

Senator BOYCE—You don’t see any conflict in service providers helping people to plan to use services provided by service providers?

Dr Chalmers—Just to be clear on that, it is not that Perth Home Care is actually doing that. They are nurturing a spot for a group of individuals, family members and others—advocates and so on. So they are almost just hosting the development of Vela Microboards. It is not part of their service arm, if you like, so there is a separation there. I understand your concern. Over about 18 months now we have been taking it steadily, investing in training for family members and what have you, and they are the ones who are translating the North American and UK microboard type experience into a local context here, including all of those things like governance arrangements—what is going to be acceptable—accountability arrangements and quality of service arrangements. Many of them are using some of the other structures that we have listed in our submission: community living, family living arrangements and so on. We have also been working with that group around the funding parameters that are available for people to use within that Vela Microboard context. It is still embryonic but they are progressing well and I am pleased to say that a significant number of families are starting to explore that space.

Senator BOYCE—Are there microboards up and functioning, or not?

Dr Chalmers—Yes, there are.

Senator BOYCE—How many, roughly? Would you know?

Dr Chalmers—Do not hold me to this but I imagine it might be around 30, 35, something like that.

Senator BOYCE—So it is a significant number to start with.

Dr Chalmers—Yes.

Senator BOYCE—So what control, if any, does the commission have over the constitution, for example, on the microboard?

Dr Chalmers—We would want to know that there is a governance arrangement in place. We would want to sight that. We would also want to know that there is a support plan in place. We would also want to know, obviously, the funding parameters that are flowing. I will give you an example. I mentioned before that we use the vast bulk of the dollars we get from government to provide individualised funding to people. Some of that funding is dollars that people will immediately go to a service provider and get services with, others will use their local area coordinator to self-manage their own funding—and that has been going on for two decades—and others will want to use that within our microboard context.

Senator BOYCE—And where would the money sit if there is a microboard involved? Who actually has control of the money?

Dr Chalmers—The money would flow to the microboard itself and that is why it needs to have a governance arrangement that is fairly robust.

Senator BOYCE—What is its structure? Is it a company or an incorporated association or what?

Dr Chalmers—Again, there are variations in that. Some of them are set up in various forms, various legal entities if you like. Part of the embryonic thing is that they are still exploring that sort of stuff. When Mr Dainton wanted to go down the path of establishing a company, that was taking us into new ground. So they become a one-person non-government organisation built around the person so that they have to have a constitution and have it lodged as a non-government organisation would have it lodged.

Senator BOYCE—There have in the past been a small number—but nevertheless a number—of parents and others who have set up or become incorporated associations so that they could be their own service providers. That would have happened in the past in WA, would it?

Dr Chalmers—Oh, very little of that. If it was done it was not done a lot in relation to the Disability Services Commission. It might have been done as a private deal.

Senator BOYCE—I know of it being done in relation to just simply accepting the funds and being the service provider that developed the services that you wanted rather than the services that were on offer. I know of numerous examples in Victoria and Queensland. I must admit I do not know any WA ones.

Dr Chalmers—I do not think it has been a big part of the landscape here and we could speculate on why that has not happened. We have hundreds and hundreds of families—individuals—who basically self-manage the dollars from government anyway, simply through the conduit of local area coordinators. That has been going on for a long time. It is really part of the landscape here.

Senator BOYCE—Sorry, could you just explain that a bit more. Is the money in an account which the local area coordinator is in charge of? Can you just explain what it means practically?

Dr Chalmers—In pretty simple terms, when an individual is allocated dollars out of our system because they are prioritised as being in high need of support, they can choose to have that flow through the local area coordinator. It means they need to develop a simple plan on how they are intending to spend those dollars, and those plans are reviewed every year or two years. Then based on that plan, dollars can flow in one of two ways. The family or individual can either spend money, and then seek a reimbursement through their LAC for that money they spend, or they can get a payment in advance and have regular payments flowing to them that they then acquit back to the LAC for how they have spent that money based on the plan that has been developed.

Senator BOYCE—So provided there are moneys left in the account they do not have seek approval from the LAC as to the way it is spent.

Dr Chalmers—Correct. It just needs to relate to the fairly simple individualised plan that has been developed.

Senator BOYCE—And who has agreed to the plan?

Dr Chalmers—At the time that the dollars are made available to the individual or the family then I suppose negotiations take place—they have done for years and years—between the individual family and the LAC.

Senator BOYCE—Who is there on behalf of the commission.

Dr Chalmers—Correct. I have got to be clear: there are certain parameters around the use of the money. It cannot just be absolutely anything the individual wants to spend it on. But the parameters are fairly broad and most individuals and families feel pretty comfortable that it is broad and it is very flexible.

Senator BOYCE—You have just outlined why I do not accept any government funding for my daughter with a disability. I have managed to raise two other children without disabilities without needing the government to help me do it and I am not going to do it this time, but that is a different issue. You overheard me saying that in Queensland the LAC system has functioned in various ways for probably 12 years or so now. It appears to be somewhat reliant on the quality of the individual LAC in many cases, certainly from what parents and carers say. Could you respond to that?

Dr Chalmers—I will respond firstly by saying that local area coordination in Queensland is very different to local area coordination in WA. I can say that with some confidence because I know many of the LACs in Queensland.

Senator BOYCE—What are the differences there, please?

Dr Chalmers—Like in the Northern Territory, when it started to experiment with local area coordination it was seen to be more of a technology than a strong values based support mechanism for individuals and families. We always get a bit nervous when, as regularly happens, we get either bureaucrats or politicians saying, ‘Give us the manual and then we will just roll that out somewhere else.’ New Zealand is the current one and Scotland, I think, has the closest replica of what we have developed here. It has taken us 22 or 23 years to build what we have got here. It is a very strong values based support arrangement that goes state-wide and I would not want to say that it is replicated in other jurisdictions as we have it here. It is more than a technology, much more.

CHAIR—We have been talking today, for example, about the Northern Territory’s one-stop shop. It is not just a portal—that is what you mean, isn’t it? Is that what you mean? I am not quite getting what you mean when you say it is not just the technology.

Dr Chalmers—I am happy to talk about my own views about the flaws in the concept of a one-stop shop too, but we might leave that for another day. Local area coordination depends on the relationship that gets built between the LAC and the people they are supporting. It also depends on the LAC building a knowledge base around not only an individual but the family, the people that are around them, their supporters, their networks, the local community and the circumstances of the individual. We have got LACs that have been in enduring relationships with the individuals and families for over a decade, in some cases 12 or 13 years. It is an enduring relationship in many cases. So it allows the LAC to take on more of a role than just that of a passing social worker who might come into a person’s life for a particular critical incident and then leave them again.

Relationships are important. The values framework is about realising that the power, control and decision making should rest with the individual and the family rather than the local area coordinator. The advocacy component is critical to the role. Our LACs, even though they are technically public servants, play a strong advocacy role around individuals. They also provide a very strong link to mainstream and specialist disability services beyond the LAC themselves. So you have to see the thing as a composite. When it comes time to focus on planning, the LAC is pretty well placed to either assist the individual family carer around planning or to draw in expertise that might be needed around planning, at any point.

Can I also add that earlier last year, we drew PricewaterhouseCoopers into our world. We currently support close to 9,000 people with disabilities plus their families—around that number. We said, ‘Go and pick at random anyone you want to go and talk to for a few hours each and sit down and just ask them what they think about the value of local area coordination and so on.’ It is fair to say that what we got back was a ringing endorsement from across the state about the value of LAC to those people.

Senator BOYCE—Is that report publicly available?

Dr Chalmers—Yes, it is. I think it might be on our website and we can also send you a copy, if you like.

Senator BOYCE—That would be good. Thank you, Dr Chalmers. What is the level of unmet need for LAC services?

Dr Chalmers—There is no unmet need. Every year for the past 22 years we have been putting additional resources into local area coordination to keep pace with the number of people who are eligible for it.

Senator BOYCE—But you need funding, do you not?

Dr Chalmers—Yes. Every year we have had additional funding over the past 22 years.

CHAIR—Is it not the point, Dr Chalmers, that the issue of unmet need is about the number of people actually applying for support or funding packages? That is the issue of unmet need. The point is, for those that do manage to get funding—

Senator BOYCE—There is an LAC.

CHAIR—there is an LAC.

Dr Chalmers—Absolutely.

CHAIR—But if you do not have funding can you use an LAC? Can you go to this expert on disability service provision et cetera if you do not have a funding package?

Dr Chalmers—Yes. In fact, a good proportion of the people that are linked with an LAC do not have an individualised funding package. I would have to say that one of the reasons they have not been required to put their hand up for individualised funding packages is the work that the LAC does within the local community to keep informal support networks in place.

CHAIR—They provide support for anybody who has funding support and I think you said there are 9,000.

Dr Chalmers—Yes. I think we need to separate local area coordination from funding packages. If I start with LACs, it means anyone who is eligible for support from the commission—people with intellectual, physical, neurological or cognitive disability.

Senator BOYCE—Would that be anyone who is eligible for a disability support pension?

Dr Chalmers—It is not an exact overlay but, yes. People in our world who have severe or profound disabilities are eligible to get the support of a local area coordinator.

CHAIR—Let us touch on the difficult issue of mental health and where it falls.

Dr Chalmers—Mental health?

CHAIR—Yes.

Dr Chalmers—Okay. Many of the people that are supported by local area coordinators who have a dual diagnosis of, let us say, intellectual disability and a mental health condition, or cognitive impairment and a mental health condition, will also be eligible for LAC support. But if someone has a stand-alone diagnosis of a mental health condition then they do not become eligible for local area coordination.

CHAIR—Thank you.

Dr Chalmers—Last year, with the formation of the Mental Health Commission in Western Australia, the new mental health commissioner, who used to be one of my senior staff, is very interested in looking at a local area coordination concept within the mental health world. It is the Department of Health here in WA that has responsibility for mental health services.

CHAIR—We had some very good evidence this morning from the Mental Health Council. We were talking about planning and their falling between the stools in terms of access. That is why I was following it up here.

Senator BOYCE—One of our key terms of reference is trying to work at out ways of answering that question for ageing parents and carers: what happens can when I can no longer care? Could you talk about the LAC system or anything else you have that is designed to ensure that there is still someone caring about the quality of a person’s life when their parent or carer cannot?

Dr Chalmers—I am sorry, I lost you halfway through there. What was the second part of your question?

Senator BOYCE—This goes back to the concepts of the Canadian model like PLAN where—irrespective of the level of accommodation, services or whatever you have provided—the only way to protect a vulnerable person is with people who care. A part of the reason for this inquiry is to look at how you try to develop a system that provides for when parents and carers are too old or die and cannot care any longer about the quality of services or the quality of life being provided to their child with a disability. Could you talk a little about how the LAC system would kick in when parents are no longer around or any other alternatives that the commission has developed in that space?

Dr Chalmers—I have been part of disability services here for 20 years now and can speak with reasonable confidence about some of the trends around what you have just spoken about. When I first joined the world of disability services, the focus of many young parents, parents in middle years and older parents was: how can you guarantee that I can get a place in an accommodation facility for my son or daughter? How can they get a group home place or a place in one of our hostels? We do not run those anymore. I do not have those conversations anymore. I do not think they happen all that often.

Senator BOYCE—They certainly do happen on the east coast, from some of the evidence we have taken from groups in the past couple of months.

Dr Chalmers—I am sure they do on the east coast. I am just reflecting on my observation from here. I have a lot more conversations with families who are saying, ‘How can we get the help that we need to build a strong support network around our son or daughter?’ rather than having a son or daughter put in a place for the rest of their life. That is where we have made significant investments in things like our community living strategy and our family living strategy. I am happy to send you material on these.

The demand for that has exceeded our expectations. It is all around building a network of support and all of the building blocks of a good life around an individual rather than pretending that if you get a place somewhere that that is magically going to lead to a good secure life for someone. My observation is that if you go about building a strong enduring support network around someone with all of those building blocks, you do build a good life and the guarantees around that are much stronger than if you hang your hat on finding a place somewhere to put someone.

CHAIR—I want to follow up on a particular issue, because it relates directly to that. That is this issue of family trusts that you mention in your submission. This committee has done quite a bit about special disability trusts and the legislation. I wanted to ask you about your submission as it relates to special disability trusts. In your submission you talk about the Land Tax Assessment Act and the rates and charges act. Could you explain those changes a little and how they relate to the Commonwealth legislation on special disability trusts?

Dr Chalmers—I am going to be upfront here and say that I do not have the fine-grain detail around these. It is still relatively new and the take-up rate, I think, has been limited. That tells us that we need to do more in that space in better informing people about the potential that exists in that area.

CHAIR—Is this a separate WA process to the Commonwealth trusts?

Dr Chalmers—Yes.

CHAIR—I get a lot of representation from WA families focusing on the national legislation because there are still some barriers there. I know the Commonwealth is fixing some of them and they are continuing, but there is still the issue of where they have purchased a home and put it into the trust that is still impacting on their pensions.

Dr Chalmers—We understand that it is still very restrictive.

CHAIR—Even the WA one, do you mean?

Dr Chalmers—No, the Commonwealth one.

CHAIR—Yes, it is. We are still working on trying to get that fixed. What you are saying is that there are alternatives in WA, specifically.

Dr Chalmers—There are some benefits that accrue from this, such as the land tax exemption. It is not trying to replace the Commonwealth opportunities; it is in addition to them. We do not believe that we have, perhaps, done enough to sell the benefits of that for people who are in that space.

CHAIR—I am a bit confused. Are you saying WA has done a bit more to make the concept of a trust more attractive?

Dr Chalmers—Yes.

CHAIR—Okay, I am on the right page now.

Dr Chalmers—It is almost like a Venn diagram where two circles sort of overlap but also do not overlap. They are two different territories. We are happy to provide additional information on that.

CHAIR—If you could, that would be appreciated. I must admit I am still a little bit confused. I have a bit more clarity, but if you could provide some more that would be great.

Senator BOYCE—And a little bit about the cost of doing this would be useful too.

Dr Chalmers—Do you mean the administrative costs?

Senator BOYCE—No. The loss of revenue, I suppose, is what I am talking about.

Dr Chalmers—Yes, for sure.

Senator BOYCE—The cost to the budget bottom line is what I mean.

Dr Chalmers—The cost to the state?

Senator BOYCE—Yes.

Dr Chalmers—Sure. I am not sure if you have our community living strategy material. It is pretty succinct but pretty powerful stuff, based on what I mentioned before.

CHAIR—We have what you included in your submission but nothing extra, no. In your submission there are a couple of paragraphs about it but we do not have anything beyond that, other than when other people have mentioned it. I have run over time but, as you can see, we are very interested in what you have to say. It is fairly well acknowledged across Australia that we are different in WA, you are right, and that there are some significant initiatives that people have shown a lot of interest in.

Dr Chalmers—Yes. There are things we can learn from the east, I am sure. We are in fairly regular contact. There are things happening in Victoria that we have our eye on at the moment. We do get a regular parade of people from the east over here, which is a good thing.

Senator BOYCE—Indeed.

CHAIR—Thank you very much. Your time is very much appreciated and if you could send that additional information that would also be very much appreciated.

Dr Chalmers—Terrific. In terms of that material taken behind the screen, will we just get a copy of that for you to have a look at?

CHAIR—Yes, get a copy to have a look. It is treated as in-confidence material. If we want to refer to it in our report, we will get back to you to talk about the bits that we might want to refer to.

Dr Chalmers—Excellent. I wish you all the very best with this. It is an important piece of work.

CHAIR—Thank you. It has been fascinating.

Proceedings suspended from 3.55 pm to 4.10 pm

HITT, Mrs Lorraine Margaret, Chairperson, Planned Individual Networks Inc.

Evidence was taken via teleconference—

CHAIR—Welcome. I understand you have been given information on parliamentary privilege and the protection of witnesses and evidence?

Mrs Hitt—That is correct.

CHAIR—I would like to invite you to make an opening statement and then we will ask you some questions.

Mrs Hitt—Thank you for the opportunity to appear. I am the mother of a 47-year-old man who has multiple disabilities. Over many years I have built a really good life for him. He is living a safe, secure life with a network. He is buying his own home. My endeavour is to support other families in the mission to find a really good life for their sons and daughters, particularly those that are vulnerable, because we all have that terrible fear of what will happen to our sons and daughters when we are no longer able to care for them. The network that my son has gives me quite a level of peace. He has a number of people in his network that keep in regular contact with him, do social things and help him plan for technology and a range of things. It takes away some of the role I have had in the past. That is my opening statement and I am happy to talk about Planned Individual Networks if that is what you would like.

CHAIR—Yes, please.

Mrs Hitt—Planned Individual Networks was modelled on the very successful Canadian Planned Lifetime Advocacy Network when they came out way back in 2002. We formed a group of parents—it is a family leadership initiative—and we did the PLAN training and we went through the set-up stages. We have been in operation for some years now. Our primary goal is to develop individual networks. We have 16 in various stages of exploration, including exploration, development or maintenance. We have 25 lifetime members. We have nine who are not at this point in time ready to start their network but have become lifetime members so that when they are ready they can. We also have 60 associate members.

The easiest way of explaining the network is if you think of a bike wheel. The person at the centre is the person with a disability. That is the hub of the wheel. The spokes are the people who freely form a relationship with the person at the centre. It may be family, it may be friends, it may be neighbours or it may be somebody that one of the family members has a connection with but who has shown an interest or has similar goals and interests.

The areas that people can look at particularly are friendship and social contact because people are quite isolated when they have a significant disability. The other areas families are quite concerned about are financial advocacy, medical advocacy and planning. Often a family member—and most often the mother—will take this on. If you have got a number of people in the network then the role is shared and supported, so the challenge is not so great.

In the planning area, there are things such as technology—environmental controls, wheelchairs, lightwriters and those sorts of things. Home and lifestyle planning is making sure they have the home and the lifestyle they want rather than what is currently the case—the old nursing homes and hostels. People with disabilities want the same sort of life as any other person and I believe we should be able to support them to that achieve that. It also looks at education, because some people have left school without the full education that they need and we all learn throughout our lifetime. The other one is employment and possibly setting up their own business. So instead of being someone who receives a service they can actually be providing a service.

There are many facets and it is as individual as the person and their network, and people within the network itself support each other. A couple of years ago, three tragic things happened in my son’s network where somebody miscarried for the fourth time, somebody’s son suicided and one of my son’s network members who he had known for years went in for minor heart surgery and passed away on the table. That actually strengthened the network and brought them together. As well as the network, we have quarterly orientations for which we do not charge. PIN is a fee-for-service provider because we have no recurrent funding. As well as the orientations we run Safe and Secure Workshops for Families, because often it takes families a long time to grasp the need to plan and prepare for the future when they are no longer there. It includes building relationships because without relationships people feel very unsafe. It is looking at home and lifestyle options: whether or not they are able to buy homes—we have one person and possibly a second one who will be buying a home; estate planning, which includes wills and trusts, which are tested entry in the special disability trust; and supporting them to learn about insurance—life insurance, income protection, and trauma and accidents.

What we have found from these workshops is that sometimes families are so bogged down in their day-to-day lives and the challenges they face that sometimes life is great, but then they go away and life just becomes too difficult. We will be holding monthly meetings to work through the book and share ideas and thoughts—that is the *Safe and Secure* book. It is a Canadian planning book that we have adapted to Western Australian legislation. It is a really useful book that has worksheets that help families look through every aspect of planning. We also do some planning for the future with people centred thinking and planning, because people often are not sure where to start with that.

We have had a lot of challenges, despite the fact that it is a brilliant organisation that is changing people’s lives. We were fortunate to receive three grants from Lotterywest that helped us start up, and we have had two grants from the Disabilities Services Commission. However, these grants are non-recurrent. We have also had donations, membership fees and a few fundraising things. But this year we need to be looking at where we can get additional grants from or approaching philanthropists to support the concept, not on a donation basis but on the basis of what we can provide back. We have found that wherever we present—whether it is Rotary clubs or service clubs—everybody knows somebody who has a disability or has somebody in their family who has a disability. So we would be looking at providing training in return for sponsorship. It is looking very different to the not-for-profit organisations which receive ongoing grants and provide services. We are looking at encouraging people to take control of their own lives and build in safeguards.

I am not sure how much more I can go into other than to say we have a board that is comprised of: a businessman, who is quite successful; a physiotherapist, who has a human service background with extensive experience; a local area coordinator, who has a degree in human service management and quite a broad extensive human service background; a financial planner; a retired businessman; and a woman who works in the disability field.

Senator BOYCE—That is your committee of management?

Mrs Hitt—That is correct; that is the board. We also have families support us with mentoring other families and we have morning teas where families get together to hear the stories of those families that have started planning and building good lives, because it is these families that other families take notice of. I am not sure if there is anything else you want me to talk about, but that, in a nutshell, is what we do. We are very proud of it and we love what we do. It is challenging because the other difficulty we have is that our existing resources prevent PIN from employing a CEO, and there is a perception by many families still that the government will provide all.

We are aware that the government cannot and will not provide all and that sometimes doing things yourself brings about really good outcomes for the person with the disability and their family. So I guess it is about changing attitudes as well as the work that we do. We have had somebody from South Australia attend our workshop, which I thought was really great. The challenges that we face are not having the funds for a CEO, and changing the perception of some families.

CHAIR—Thank you. That is a really good start in terms of giving us an idea of what PIN does. Senator Boyce is champing at the bit to ask some questions.

Senator BOYCE—Do you have any people with mental illness amongst the families that are involved with PIN?

Mrs Hitt—Yes, we do. We have a person with a dual disability—intellectual disability and mental health. These are vulnerable people—people with mental illness, people with dementia or ageing, people with disabilities, Indigenous people. It can apply to many people that are vulnerable.

Senator BOYCE—We had some evidence this morning from the Mental Health Council of Australia suggesting that some of the ways that government programs and special disability trusts are set up make it more difficult for people with episodic disabilities to access some of the things that are currently available.

Mrs Hitt—I would agree.

Senator BOYCE—You would be aware of the FaHCSIA booklets around succession planning. I think there were two booklets brought out about four years or so ago.

Mrs Hitt—Yes.

Senator BOYCE—Could you comment on those booklets?

Mrs Hitt—It has been a while since I read them and I would probably like to go back and have a look at them before I made comment again.

Senator BOYCE—If you have the time to do that it would be useful. We know they exist. Whilst they appear to have been distributed very widely there is obviously some disconnect between those booklets and families in that it has not translated into vast numbers of people going out there and doing succession planning.

Mrs Hitt—I guess the key thing for me is that a book, alone, will not do it. As I said, our training is all based on that booklet we have, but unless you have people back in little work groups working through it, parent to parent, it just does not seem to go anywhere.

Senator BOYCE—Could you talk a little about how PIN goes about setting up networks?

Mrs Hitt—Yes, we usually encourage people to come along for the orientation and the workshop so they get an understanding of what PIN is and what we do. Primarily, the people that we support at the moment are 18-plus, although we have realised that it would be very good to start with children who are transitioning from high school, because often they lose their friends, who could become very good parts of the network. We have a network and membership coordinator. A family member will go and talk to the person and listen to what their expectations and hopes are. Sometimes they do not fit well with PIN—they want funding—and we talk to them about funding and where they can go for that, but we also say to them that funding alone is not the answer. We tell them that what you need is a very strong plan and you need to focus on who the person is, what their gifts and passions are, what contributions they can make and who they have been connected with in past years. We get them to think about and write down all of the people that have passed through their life that really had an impact on them. From there we encourage them to invite them to a social function. We talk about sharing the stories, sharing the history and through hospitality.

We did it with my son, who has no speech, a severe language disorder, cerebral palsy and autistic traits. I wanted him to be very much a part of the person centred planning process. So I got photos of him from the day he was born right through to the age of 46, when he did it. And the people who came along to that person centred planning sat alongside him at various points. When the photo was shown—he actually controlled it; he put up the photos—the person who was with him at that time would tell the story. It created cohesion and it brought back memories of the good things that they had done. From that person centred planning we were able to get a number of people to join his network.

Senator BOYCE—How many people are in your son’s network, as an example, Mrs Hitt?

Mrs Hitt—He has an uncle, two cousins, a lady who used to be a paid support worker who no longer works but who is absolutely committed to him. There is also a man with whom I was doing some social role valorisation in preparation for someone to come over to Western Australia and do the training. We had a lunch afterwards. He was sitting on one side. There was a lady who I used to pay to take my son out and we were talking about his network. This guy said to me afterwards, ‘How can I get involved?’ He used to take my son to football whereas before we used to pay somebody. He never ever misses the football; he arranges his holidays and everything else around it. But over the years he brought his wife along and they have had a little boy who is now 18 months old. He also goes to the football. They come to his birthdays. If things are not working well, they will be up here checking out what is happening. And there is a neighbour. At the moment we are looking for possibly a couple of others who can help connect him—he has a wide sporting interest—to some of these local sporting clubs with a view, beyond his sport and the spectator sport, to connecting with people and bringing more people into his life. We are looking at him perhaps joining Neighbourhood Watch so that he is contributing and giving back by delivering the pamphlets.

But each network is different, and it is based on the person, their family, who is in the network and how it operates. In the early stages people actually pay $1,100 lifetime membership and they pay $35 an hour for the facilitator’s time. Each network has a facilitator. The facilitator is the only person who is paid. People in the network freely give their time and support.

Senator BOYCE—Are they a PIN employee?

Mrs Hitt—They are employed by PIN but they are selected by the person, because unless that relationship forms then it does not work well. The networks are all very different. In the early stages it is important to have at least once-a-month meetings. It might take 10 hours or maybe a little longer with the coordinator to work through the early exploration stage and how they process that. I have got quite an extensive background in human services so I hurried my son along quite quickly because I knew what to expect. But if you have a family that does not have that background you would need a good 10 hours minimum, and then you have the network happening once a month for the first year. We found, because we have been going for a long time that we have one meeting with the facilitator and one meeting where there is a social gathering for people—we have a meal or go out somewhere. I have lost my train of thought.

Senator BOYCE—You were just talking about the frequency of meetings and style of meetings.

Mrs Hitt—And the other thing is that people within the network will go to visit him or go out with him in between, so a lot happens. We have found that when you are between facilitators there is a tendency for the network to not meet as often, or to slow down a lot. Without that facilitator, it tends not to work as well.

Senator BOYCE—So you are seeing the facilitator as having—

Mrs Hitt—A key role.

Senator BOYCE—a full-time role. They are not just someone who comes in and out when there are problems with the network.

Mrs Hitt—No, they are there. We have a reporting mechanism whereby the facilitator will do a summary report. It is done in a very informal way, often by newsletter with photos, and we talk about what has happened and do some planning for what is going to happen. It is an intentional strategy that keeps the whole network moving.

Senator BOYCE—The purpose of this obviously is long-term planning—

Mrs Hitt—Absolutely.

Senator BOYCE—for when the parents or carers cannot care, for whatever reason. What safeguards have you built in there around the sustainability of the network?

Mrs Hitt—I will talk about the facilitator first. If somebody moves out of the network for some reason—marriage, kids, moving interstate—the facilitator will work with the group to bring in somebody else. If the facilitator leaves for some reason, the coordinator steps back in and goes through the process of recruitment, matching and getting the new facilitator sorted.

Senator BOYCE—That would be PIN's coordinator, and that person would be the employer of the facilitators. Is that how it works?

Mrs Hitt—Correct. And she trains and supports facilitators. They are the key positions. The coordinator is essential and the facilitator is essential to the wellbeing of a network.

Senator BOYCE—Yes. So, as long as there is funding to pay their wages, there is no reason for that not to last forever. Is that basically what you are saying?

Mrs Hitt—Absolutely. As well as giving peace of mind for when the parent is no longer there, it builds a good life along the way. It increases self-esteem. It is just so beneficial.

Senator BOYCE—What role, if any, would you see for the federal government in providing for the PIN style of looking after a person with disabilities in the long term?

Mrs Hitt—We have individualised funding in Perth. It would be really nice, particularly, if the national no-fault disability insurance comes in and if that could be used flexibly. Families value PIN and the work that we do, and it leads to them having a much better life.

Senator BOYCE—You mean if the NDIS, or even current funding, could be used by the family to pay for facilitation services, for instance?

Mrs Hitt—Yes. That would be very beneficial because at the moment there is a perception by some that it is elitist. That is not entirely true. We have some families who are lifetime members who do not have a great income, but they are very strategic in how they manage to get the funds for the facilitator. The other thing is, if we know somebody is not able to meet the full cost, we can stage meetings with the facilitator and have other support so that the network keeps moving. But it is far better to be able to do it strongly and well in the beginning, because that cohesion is the thing that keeps the network safe and working well.

Senator BOYCE—We have also had some evidence from WA on microboards. Could you talk about that and how you see that relating to what you are doing?

Mrs Hitt—Microboards were set up when Linda came over from Canada and they are under the umbrella of her homecare services. Their aim is to set up a microboard that funding can be channelled through. At the moment we are looking at how we can work together more closely, because the microboard is the thing that helps look at funding. They have a group of, say, four or five people who would be the employees and who would manage the person's individual funding in the cases where they are vulnerable and at risk. So I see them hand in hand with PIN; they are a very valuable organisation. We would like to work more closely with them, and I am working towards that end.

Senator BOYCE—But not as alternatives?

Mrs Hitt—They are very similar to us. They are a ‘user pays’ service; people pay for their support.

Senator BOYCE—Could a microboard fulfil the role of supporting the person when the parent or carer is not around anymore?

Mrs Hitt—Financially, the networks that we have provide a holistic approach to social, financial, planning and medical care. Often the mother advocates for operations or surgery, or anything that needs to be done, so you need somebody within the network who is very strong and who will take on that role.

Senator BOYCE—I like to encapsulate it as a quality monitoring role.

Mrs Hitt—Sorry, can you repeat that?

Senator BOYCE—The way I sometimes try to describe it is that the network would play that quality monitoring role that parents and carers often play.

Mrs Hitt—Yes, it is partially that, but it is a number of other things because without the network the life of the person would not be so rich socially or otherwise. It is a safeguard because, as you would know, it does not matter what organisation or what style of accommodation, there is always the risk for somebody who is very vulnerable, whether it is because of age, mental health, or disability. I think it is really important to have those strong advocates around the person to make sure that they are well and healthy.

Senator BOYCE—Yes.

CHAIR—Microboards and the networks could complement each other, couldn’t they?

Mrs Hitt—They absolutely do, yes.

Senator BOYCE—We were told just a little while ago by Dr Chalmers that there is no unmet need in the disability area that is not being currently addressed by local area coordinators. Can you comment on that view?

Mrs Hitt—As a PIN chair, I would not be able to.

Senator BOYCE—No.

CHAIR—You might have answered this question and I have misinterpreted or not picked up on what you said. How many families can a coordinator support while still being effective and not skimping on that support?

Mrs Hitt—In the Canadian model, they say 25 and then they bring in a senior facilitator-mentor, who mentors with facilitators so it is shared in a different way.

CHAIR—You mean if you get more than 25?

Mrs Hitt—Twenty-five workers. We have 16 at the moment that are in various stages. If you had 25 networks all up and running together, that would probably take the coordinator’s time. We have a coordinator that is currently working 30 hours a week. So, yes, I would say that 25 would be absolutely the maximum for her.

CHAIR—Okay.

Mrs Hitt—If people could afford the service, there is no reason why it could not be expanded.

CHAIR—So you could have more than one coordinator in a service?

Mrs Hitt—Absolutely, yes, and PLAN Canada does. They have a brilliant website. They have been going for many, many years and they have 100 networks in various stages and various places, with a number of coordinators and mentor-facilitators.

CHAIR—Thank you.

Senator BOYCE—Two distinctions between PLAN and probably what can be done in Australia are that PLAN require that the home be owned and they do not accept government funding. Do you see that being a potential possibility in Australia?

Mrs Hitt—We do not require people to own their own home. We have people who are still at home in their parents’ home. We have some that are renting. We have said that we will not accept government funding. If people are funded themselves and they can use the funding that they have to buy services from PIN or Vela Microboards then that would be absolutely fine. It is just that PIN wants to be able to be a strong advocate for families, and if you receive government funding it is not always easy to do that.

Senator BOYCE—No. The sustainability of the organisation can be somewhat at risk too, depending on whether you are the flavour of the month for funding or not.

Mrs Hitt—Yes.

CHAIR—I want to go back to the issue about funding. The networks could be advocates for the person for government funding, for government services?

Mrs Hitt—Did you say for aged?

CHAIR—No, for government services. The facilitator could help the network advocate for government funding and a package for an individual, for example, but the organisation itself will not and does not take government funding.

Mrs Hitt—No, I was saying that we do not advocate for funding for people. There is a process that they go through, and we do tell them how to get that support. What I am saying is that if people have funding and they are able to use that funding to pay for a facilitator then we would be happy to do that. We would not be seen as taking the money from government, we would be taking it from families.

CHAIR—Okay.

Senator BOYCE—Say you have gone through looking at what constitutes a good life for a family and their member with a disability and, in amongst that, is a need for a service or a piece of equipment or something that would require government funding. Your facilitator does not try and get that, so what do you say then? How do you work then with the family on that issue?

Mrs Hitt—Families have to have services, they need to have equipment, and it comes via the government, inevitably, because of the funding. We just complement the services and supports that are out there in a way that builds that safety and security and builds people a good, fulfilling life.

Senator BOYCE—So you would, say, go and talk to the local LAC or something, would you?

Mrs Hitt—We would refer them to the local LAC. We might give them information on the independent living centre. We have never been asked but we would probably write a request for a grant to Rotary or somewhere like that if people needed it, or somebody in the network might do that. It is really as broad as that network and its members choose to take it. I know that some network members—one in particular is a very strong advocate—did go and talk for that person and with that person on an area of concern for them and that had a really positive outcome.

Senator BOYCE—How does PIN relate or interact with the LACs?

Mrs Hitt—LAC is another service, the same as any other service provider, whether it is the Centre for Cerebral Palsy or whatever. We do work closely with LACs. We get them to come along to orientations. They bring families and do referrals to us. They work in a way that builds good lives too, so they are very happy to encourage families to come to PIN or Vela Microboard.

CHAIR—How do families find out about you?

Mrs Hitt—We have a newsletter and we have a website. Whenever we are doing something we send that out via the LACs, and they have a huge number of people that they support. The Disability Services Commission has a newsletter that goes out to service providers, so they will send that out to them. There is also word of mouth—families talk about PIN; agencies do.

I have just come from a meeting earlier with the Department of Housing and Works about Keystart and Access Home Loans. We had a group of families there listening to the possibility of people buying homes should they choose to do that. We do believe that if you own your own home it is the Australian dream and it gives you security—and it is possible, but it is up to people to choose the life that they want.

Senator BOYCE—Would you have any suggestions about how special disability trusts or the Western Australian family trust system might be changed or improved to make that easier?

Mrs Hitt—We have put in a submission. Harry Weir, the past chairperson, who was on that committee and Michael Sayer, who is on our board and is a financial planner with lawyers in his company, have been very involved in feedback. I guess it is quite restricted at the moment because it can only be used for accommodation or housing. It cannot be used for the other things to help people live a good life.

CHAIR—Are you talking about the—

Mrs Hitt—Special disability trusts.

CHAIR—The Western Australian part of it or the special disability trusts?

Mrs Hitt—Special disability trusts.

CHAIR—Do you know they are changing it? It is still not going as broad as a lot of us would want, but they are changing it to better address, for example, medical needs so it not just medical needs associated with a disability anymore?

Mrs Hitt—I was aware of that being submitted to them. I was not aware that they were about to change it yet.

CHAIR—That is the intention.

Mrs Hitt—That would help.

CHAIR—In fact, I think that has already happened.

Senator BOYCE—I thought it had happened.

CHAIR—That bit has already happened, but there are more changes about to go through. They still do not go as far as a lot of us feel are necessary. For example, they are still not adequately dealing with this gifting issue—if you have already bought a house for your son or daughter, that affects your pension et cetera. There are still various issues, but it is a bit better than it was.

Mrs Hitt—Recognition of the medical needs is really good, but it is like everything we have seen: if you are socially isolated, you are going to need a lot more support medically. Wouldn’t it be good to put it in earlier to prevent the medical problems?

CHAIR—Yes.

Senator BOYCE—Yes.

CHAIR—Do you have any final remarks you would like to add?

Mrs Hitt—Only that the board are absolutely committed to the model. We have seen the results and the benefits to individuals and families. We would love to spread our wings further, but we need to consolidate and make sure we have funds to do that. At the moment, we are looking at our 25 networks and working towards building very strong networks for our people. We will still be looking at philanthropy and other ways. It would be really good if families were able to buy this service through their funding. It would make it so much easier for families.

CHAIR—Yes. Thank you very much; your time is very much appreciated and is very helpful for us.

Subcommittee adjourned at 4.46 pm