COMMONWEALTH OF AUSTRALIA

Proof Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

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

TUESDAY, 30 NOVEMBER 2010

SYDNEY

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SENATE COMMUNITY AFFAIRS

REFERENCES COMMITTEE

Tuesday, 30 November 2010

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, Carol Brown 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

Committee met at 9.01 am

CLARKE, Mr Stephen George, Chief Executive Officer, Down Syndrome New South Wales

O’CONNOR, Mrs Jill, Information Officer, Down Syndrome New South Wales

CHAIR (Senator Siewert)—Today the committee continues its public hearings for its inquiry into planning options for people ageing with a disability. I would like to welcome representatives of the Down Syndrome New South Wales. I understand information on parliamentary privilege and the protection of witnesses and evidence has provided to you. We have your submission numbered 22. I would like to invite either or both of you to make an opening statement and then we will ask you some questions.

Mr Clarke—I have been with Down Syndrome New South Wales for four years. I have had over 20 years experience working in the disability and community sectors. I have worked for a number of years in group homes with people who are ageing with a disability and I have worked with people who were transitioning from institutionalised care to community living.

My colleague Jill O’Connor has worked with Down Syndrome New South Wales for over 20 years. She came originally from a nursing background. She has been a senior manager with the association. She currently edits *Voice*, the journal of Down Syndrome New South Wales and Down Syndrome Victoria, and edits a number of other publications for Down Syndrome New South Wales, including our daily blog. Over those 20-plus years Jill has talked with many people with disabilities and their families learning about the issues they face and their needs, wishes and aspirations. Jill has presented seminars and workshops on a wide range of topics for families and professional groups including on topics around ageing and planning for the future. She has talked with academics and extensively studied the literature from here and internationally gathering and disseminating much sought after information for families.

Jill has developed an extraordinary depth and breadth of knowledge about Down syndrome and related issues and gained a reputation within New South Wales and across Australia within the Down syndrome community—if you would like to call it that—for being a leading and invaluable source of information on Down syndrome issues. As well as having worked for Down Syndrome New South Wales for over 20 years Jill’s expertise is derived as much as anything else from being herself a parent of a person with Down syndrome for even longer than those 20 years. She will talk today from personal as well as professional experience.

The Down syndrome association of New South Wales celebrated its 30th anniversary last month. We were formed in 1980 by parents for parents because there was really no other way. There was no thought of government funding or support and no formal disability rights agenda or campaign to join the slipstream of at that time. We were a parent mutual support group that became an association.

Those founding members, the parents of babies and young children with Down syndrome in the late 1970s, were very much the trailblazers. They fought for early intervention services, fought for the right to take their child to the local public school—something pretty much unheard of just 30 years ago—and then later, when their children left school, they fought new battles for job opportunities and support for basic choices in accommodation and lifestyle, and they have gone on fighting for options and for services as they and their children age. Those founding members were the first generation to confront the likelihood, not just the possibility, that their child with Down syndrome would outlive them—and I will touch on that more in a minute.

Mainly because of those hard-fought and hard-won battles of the past, a child with Down syndrome leaving school today, and their parents, has expectations and aspirations higher than for any previous generation. The expectations of parents today of a young child with Down syndrome are even higher again. Nowadays long-term thinking and attempts at planning begin very early for the parents of most people with Down syndrome. With a diagnosis of Down syndrome usually delivered at or very soon after birth, some of the earliest concerns phrased are: ‘What will happen to her when we die?’ ‘Who will care for him when we can’t?’ As preoccupation with the varying demands of daily life takes hold, those concerns may recede somewhat but they are always there. As time goes on, they resurface and their resolution becomes even more of an imperative.

Like many of the groups and individuals who responded to this inquiry in writing and in the hearings so far, Down Syndrome New South Wales is only too aware that planning options and services for people ageing with Down syndrome are limited and that it is all but impossible to make reasonable plans for later life when adequate supports are simply not available to most people. The responsibility falls to the family and usually remains with them. Families have shown very willing to support sons and daughters with Down syndrome and will continue to do so. Parents do not want to hand them over to someone else but we need relief for ourselves from 24/7 responsibility, and a child with Down syndrome needs as smooth a transition as the parent can manage into life without the parents. They want their freedom and the parent wants them to have it, safely.

We know that people with Down syndrome often find unpredicted change difficult. We know how to prevent them from suffering unnecessary distress, and we need our community to help provide the means. Rather than reiterating what others have already said they would like, Down Syndrome New South Wales would like to explicitly endorse some of the submissions and the previous witnesses, including Dr Ken Baker, for NDS; Family Advocacy, on the Supported Living Fund for New South Wales; Alzheimer’s Australia, on its concern about the provision of support for those with younger onset dementia—and that is something that people with Down syndrome have a high risk of—the New South Wales CID, on its advocacy for better health outcomes for people with intellectual disabilities; and the excellent work of the Futures Alliance in making barriers to adequate supports for older people with disabilities explicit. Down Syndrome New South Wales would like to join the many endorsements for a National Disability Insurance Scheme as a means to deliver an explicit entitlement to lifetime support, and we would like to add our voice to the growing demand for the implementation of direct funding mechanisms—the so-called self-funding packages—to give people real options and control.

We would like to highlight just a few points that are very specific to adequately supporting people with Down syndrome and their carers as they grow older. Our sons and daughters with Down syndrome tell us that their dreams for a good life are very similar to everyone else’s, and that is a good starting point. They will need support, and parents will not always be there to give it. As mentioned, the life expectancy of people with Down syndrome is increasing. Parents of people with Down syndrome must expect them to outlive them and they will age alongside their siblings, and we need to plan for that. That is not in the future; it is happening now. Planning for retirement at an earlier age than usual and responding to the actual needs of individuals, whatever their age, are patently obvious needs.

People with Down syndrome are commonly living into their 50s and 60s today. It is certainly not unheard of for people to live into their 70s. There is a lady by the name of Alison Durham—I think she is deserved of her name being recorded in *Hansard*—who turned 80 in August. She lives in northern New South Wales. She is the oldest person we have found anywhere in the world with Down syndrome, and she has outlived all her siblings. She has lived now for 34 years in a nursing home, and I do not think that anybody planned for her to live in the nursing home for that length of time.

People with Down syndrome, as a group, are also known to age prematurely and to be at a significantly higher risk of developing dementia earlier than other people with and without disabilities. It is not universal, but we cannot predict which individuals will develop clinical dementia. The need for experienced, expert health services to provide accurate differential diagnosis; the poor articulation of aged care and disability services, perhaps made worse by recent public policy developments; the entry age criteria; and the unpreparedness of disability services staff are all very, very significant concerns. At the same time, we hear very little about how best to support those numbers of older family carers who will see their sons and daughters with Down syndrome suffer from dementia. There is some research and some good work being done, but we need it to be better known and to be acted upon as a matter of course. These are very difficult times for families, and we do not need to make them more so.

The first modern generation of people with Down syndrome to have been raised at home in large numbers is now entering middle age. They have had the loving, articulate support of a generation of parents who have fought long and hard for services like education, for rights and opportunities and sometimes for their children’s lives. Those parents are getting old. They are getting tired. Some—as I think has been commented by Jill O’Connor—are getting cranky. But we are not planning on going quietly—and that is another well-made comment by my colleague Jill. We share the commonly raised concerns about limited options for planning, social supports, acceptable accommodation, financial support, transition through life’s later stages, ongoing skill development and learning, and basic safety. The parents tell us that their sons and daughters are not a burden but lack of adequate support is. That is my opening statement.

CHAIR—Thank you. Mrs O’Connor, do you want to make a statement as well?

Mrs O’Connor—No, that says what I would have said—and I did say that some of us are getting cranky.

Senator BOYCE—You have talked here about the 5,000 inquiries you get a year. Some of them are: ‘What are we going to do long term?’ Could you just talk us through the sorts of inquiries these are and what the sorts of concerns are?

Mrs O’Connor—People are starting to wonder, of course, with an adult son or daughter in their late 30s or 40s, where they are going to live. That is usually the first thing that comes to mind—

Senator BOYCE—The physical accommodation.

Mrs O'Connor—the very practical concern of just exactly where this person might live. Where might they be safe? Where will they have the opportunity to be surrounded by their friends or people that they choose to live with, at least, and how do they get access to those kinds of services? There is a common belief in the community, I think, that it just happens, that somehow, magically, we must get to a point where we decide that our son or daughter needs to leave home and we ring somebody up, in a nicely funded government service, we decide on a date and it just happens. People are often very surprised to find that there is, in New South Wales at least, no such mechanism. My son is 25, and people often ask us if he lives at home with us. We say: 'Of course. Where else would he live?' There simply is not another choice for him at the moment. We do not have the means to provide him with another home, and if we did there would be no support service available. It would not matter how much money we had.

Senator BOYCE—Why is it that there would be no support service available?

Mrs O'Connor—There is not a mechanism widely available in New South Wales. There are a couple of pilot programs with very small numbers in them that will allow people who have means to provide accommodation and then tap into a service that will provide support for somebody living in that accommodation. Many families have approached government services—the Department of Ageing, Disability and Home Care—and offered a house, a flat or some sort of accommodation and asked for support services to be supplied, and there is no mechanism for that to happen.

Senator BOYCE—So, unless you are in government accommodation, you cannot have government services—is that basically what you—

Mrs O'Connor—Government funded services which are offered through a non-government organisation—but they are all government funded. There is very little access to support services unless you could fund that yourself, and of course the government finds that very expensive to do, so of course families do as well.

Senator BOYCE—Could you perhaps run us through the sorts of accommodation and the options that are there.

Mrs O'Connor—In New South Wales?

Senator BOYCE—Yes, please.

Mrs O'Connor—Anybody, of course, can live anywhere that they can afford to and choose to, but that is not a real option for most families. In government operated and funded services, currently in New South Wales it is pretty much limited to group homes, and the vacancy management programs operate at crisis level. So there is simply no possibility that you would get to the age of 25 or 30, decide you were ready to move out of home and just go and choose which one you might tap into. You cannot even have your name placed on a waiting list. There is no waiting list.

Senator BOYCE—There is no waiting list?

Mrs O’Connor—No.

Senator BOYCE—How does that work?

CHAIR—Once there is a crisis—

Mrs O’Connor—You can approach the intake and referral service of ADHC and ask for a case manager. If you are not in fairly dire need at the time, it is most unlikely that you will get one. Even if you are allocated a case manager, that is not an automatic entry; you have to wait for a place to become available. Pretty much what people tell us is that if you are alive and breathing then you are regarded as the person’s carer. So, while he has another carer, there is no place. Some people do occasionally move into vacancies—I do not know how they arise; it must be quite serendipitous—but there is certainly no automatic entitlement and there is no waiting process.

Senator BOYCE—Presumably, because it is so crisis driven, there is no choice either. If there is a vacancy, you take it or go back.

Mrs O’Connor—The policies give you the opportunity to nominate three local planning areas where you might like to live. In reality, I do not think you get very much choice, and the idea that there might be some compatibility studies or some choice about who you live with has been removed from the policy documents. It was not working; it might as well not have been there. So, when a vacancy arises, it is pretty much, ‘Take it or not.’

Senator BOYCE—So there is no psychological testing of the compatibility of the housemates or whatever.

Mrs O’Connor—As far as I understand it, that does not happen. I think services do try to move people around so that they are compatible, but they too are operating at very, very tight vacancy levels. It would leave the Sydney rental market for dead, I think.

Mr Clarke—An increasing number of inquiries from parents relate to people who already have a place in a group home, for example, but feel that it is not appropriate or that there are issues of compatibility with other flatmates or even more serious issues of violence or abusive behaviour. Obviously then that limited choice becomes a very great detriment to the person’s quality of life. So even those who do have a place in a group home are looking at what other options are available and find very limited options.

Senator BOYCE—So, as the first step of feeling comfortable that they are going to be well looked after when you are not around, it is not sounding like a very positive step for people.

Mr Clarke—In many cases, no. In some cases it works very well, but not for everybody.

Senator BOYCE—There would be other things that families or groups of people would be trying to do in terms of accommodation?

Mrs O’Connor—There are a number of families who are trying to put together accommodation and support packages which they will make a substantial financial contribution to, but many of them are meeting bureaucratic barriers that do not allow them do it. There is a group in the Ryde area that started off with 20 families who wanted to put together an intentional community of some kind, such as a small village. When they took that plan to the New South Wales government, they were told that they could do that. However, if they came to the department with the accommodation and the department accepted it, those 20 people with disabilities may not be the ones who got the places in that accommodation because it would have to go through the vacancy management system. So, of course, families backed right away from that. Who is going to put up money—

CHAIR—If you do not get your own in there.

Mrs O'Connor—when you cannot even guarantee a place for your own child. It puts people way offside from government services and leaves them very much outside of that system, and there are inherent risks in that for continuity and security.

Senator BOYCE—What is Up, Up and Away?

Mrs O'Connor—Up, Up and Away was a project run by Down Syndrome New South Wales from 2006 to 2009. It was a demonstration project funded by the Foundation for Young Australians. The aim was to get a group of young people who would work with mentors or life coaches, really, on articulating the things they considered would make a good life for them and then to help them develop the skills that would allow them to do that. The program ran for three years as a demonstration program and was highly successful. Some of those young people did amazing things. Some of the things that they wanted to do were very ordinary but they had not been able to tap into those things or perhaps even articulate what it was that was important to them. Some people learnt to cook for the first time. Some people learnt to travel independently and were allowed to by their families, who admitted that they may have been a bit overly protective. They became much more independent and felt that they had more freedom. Other people looked at particular interests they had. One young woman said that she would very much like to be a forensic scientist, and so her coach arranged for her to have a day at the University of Western Sydney with the forensic science people. She spent a day being a forensic detective and has kept up her interest in that. It would have been easy for anybody to say, 'That's not possible because you have down syndrome.' But the aim of the program was to see how far they could take this dream—and that is what they did.

Another young man came into the program and said, 'I want to be a famous actor.' Wanting to be in the movies is not an unusual ambition for a person with down syndrome. In 2009 he won the Sydney Tropfest award for best actor in the film that won best film for that award. He has had a number of roles in films since. He still works in his regular job at Macdonald's but from time to time he has to take time out for his movie commitments, and he is pretty thrilled by that.

Senator BOYCE—That was a child program and it is finished?

Mrs O'Connor—It has come to an end under the funding from the Foundation for Young Australians. They expressed a hope at the time that the ideas and concepts behind that program might develop to inform government policy, and that is actually happening in New South Wales. Currently we have a pilot program that is being funded by the Department of Ageing, Disability and Home Care that runs in partnership with Down Syndrome New South Wales and two service providers. It is adopting those concepts of very personalised support for the interests of the person with down syndrome, with a disability, as a basis for implementing person-centred planning models. The program will run over two years.

Mr Clarke—That is the Independent Living Support Initiative. It is a pilot, as Jill says, and it is about to have its first intake in February—five participants in the Hunter region and five participants in southern metro-Sydney. So it is a very small pilot project. There are a number of such pilots happening which the Department of Ageing, Disability and Home Care in New South Wales is involved in, but they are all very small.

Senator CAROL BROWN—Over the life of this pilot program, how many people would be able to participate?

Mr Clarke—Within that particular pilot project, the Independent Living Support Initiative, there will be 30 participants.

Senator CAROL BROWN—And how many participated in Up, Up and Away?

Mr Clarke—A little bit under 30 over three years.

Senator CAROL BROWN—On Friday evening the documentary that was made during the Up, Up and Away project is being broadcast on Aurora TV for the International Day of People with Disability.

Senator BOYCE—Which television station?

Senator CAROL BROWN—Aurora TV. It is a Foxtel community channel.

Senator BOYCE—Okay. Quite a few submissions have talked about the fact that there is a cut-off between disability and ageing in most states. You mentioned public policy as potentially a problem. Would you like to talk about how that happens or does not happen in New South Wales?

Mrs O’Connor—It becomes a particular problem for people with Down syndrome because of the very high levels of early onset dementia amongst people in their late 40s and early 50s. There is a very high incidence by the late 50s. The incidence of dementia amongst people with Down syndrome in their late 50s is as high as 60 or 70 per cent. It is very high by then. The problem is that aged-care services, which generally have the expertise and experience in dealing with dementia, do not kick in until 65 in most regions. So people have been turned away from those services because they are not old enough. It doesn’t matter how they present clinically or how much they are suffering from dementia. Some people have been denied access to appropriate dementia support because they are not old enough. They might be 54 but they have to wait until they are 55. There was one man earlier this year who was 59. He was living on his own in a house that had been his mother’s. He had some support that he had had for a long time, but he was not able to have an ACAT assessment until he turned 60, even though it was quite clear and he already had the diagnosis of dementia.

CHAIR—Yesterday in Melbourne we were talking about using some other tool to assist with early onset dementia rather than just the ACAT assessment tool. Have you got any opinion on that?

Mrs O'Connor—There are very, very good, well-developed and highly credible assessment tools for people with Down syndrome that were developed particularly in the UK and the US. We know what needs to be done. The differential diagnosis is very important, because there are lots of other things that can mask dementia or be masked by dementia, but the tools are available. It is not a matter of diagnosing the dementia accurately so much as getting access to the services and the ACAT assessment being the gateway for access to the services. So the tools for the assessment of dementia are well developed. We would like that information to be better disseminated and for the healthcare professions to know more about it, but it is there. We do not need to invent that. We need a way for people to get into those services.

CHAIR—Instead of using the ACAT tool, could we import those tools? Could we not reinvent the wheel but use those for decision making rather than going through the ACAT process? Or would ACAT be okay if we could just apply it at any stage rather than having 60 as a cut-off?

Mrs O'Connor—As long as it got you the services that you needed, I don't think anybody would mind too much whether it was ACAT or a separate tool—although the actual diagnosis does need to be made with modified assessments. The regular assessments that are used to assess dementia often do not serve people with Down syndrome well because they rely on cognitive assessments that people with known cognitive impairments would never have been able to satisfy, even when they were at their peak.

Mr Clarke—And that is why it is very important for people with Down syndrome and other cognitive disabilities to have some sort of baseline assessment done. We suggest, and I think Alzheimer's Australia recommend, that that is done in a person's early 20s and that then becomes the baseline against which further change can be measured.

Just getting back to the original question about public policy, the other main problem which the committee would be well aware of is the transitioning from state funded care through the group home to federally funded, and so all the issues of coordination of services and coordination of that transition, cost-shifting and all those sorts of issues then arise. But you would know about that.

Senator BOYCE—Are there any examples you could give us of people who have fallen through the tracks between states services—

Mrs O'Connor—There was an article in the *Sydney Morning Herald* in the middle of the year about a man with Down syndrome who was being cared for at that time by Hammond Care, which is a large aged care services provider. In response that there was a letter published the next day by the sister of a woman who was 59 who had Down syndrome and had dementia and she had been denied access to care on the basis of her age and had been told she could apply for a case worker but she would probably be dead before she got one.

Senator BOYCE—Most probably realistic.

Mrs O'Connor—It probably was. It is fairly confronting but it is reality. She said, 'We had to wait until something dangerous happened and eventually it did.' We are hearing more and more about people like that. We have almost got two separate cohorts of people with Down syndrome: older people who have been in care for a very long time from a different generation, and then this new generation of people who have lived at home and been raised at home and have not been in care but getting to an age where they need that level of support or a high level of support and finding it very difficult to access those services when they need them, rather than waiting for everything to fall apart. I imagine, and I do not want to imagine it very much but I have to, that it is distressing enough to watch your child start to deteriorate. To have services that might support him and you denied on top of it would just make it impossible.

Senator BOYCE—Very difficult. There seems to be an assumption made in some of the submissions, and certainly in some of the policy approaches to long-term care of people with disabilities, that the majority will stay home with their parents until the parents can no longer care. Could you talk a little bit about what you would think of as the ideal there? Is it that they move out sometime in their 20s, or whatever?

Mrs O'Connor—One of the dilemmas that arises for parents is when is the ideal time for somebody to leave. We expect our other children to leave home and sometimes we wish they would go a little earlier than they do, or a little less often than they do. When you have a child with a disability, this happens at various times in their lives but it is very stark at the time when you are thinking about are they going to live somewhere else. Do we wait for them to develop the skills to be able to do that or do we set the plan in place and when they have moved then they will develop the skills? There are arguments on both sides. Many parents feel quite protective and will say, 'But he's not ready, he can't do all the things that he needs to do to be able to live independently.' The counter argument is that he will not be able to live independently until he gets the opportunity to do that and then he will have to do certain things. While he is at home with extremely good hotel services often, why would he develop those skills? As a personal example, about a year ago somebody told me about her son who was 15 who had Down syndrome and how he did his washing independently each week. I thought, 'I've got a 24-year-old who I don't think has ever put anything in the washing machine. I'd better see if he can do it.' It turned out that he could. He now does his washing quite independently and is quite proud to do it, but while ever I was going to do it why would you? I mean, if someone came in and did my washing—

Senator BOYCE—I do not think you need a cognitive impairment to—

CHAIR—I was just thinking that as well. My 21-year-old did not pick it up till he left home.

Mrs O'Connor—But sometimes we need a bit of a push as well as they. My son is 24. He tells us that he is not quite ready to move out yet; he will let us know when he is. Perhaps what he would like is that he knows where he wants to live and we could leave when he is ready to have it all to himself pretty much. That would probably suit him. I can imagine that perhaps in about three to five years he might start thinking about that. At the moment he says he is not ready, and he does have a very significant developmental delay, so it is probably not reasonable to expect that at 18 he is going to up and leave home.

Senator BOYCE—But it has been discussed.

Mrs O'Connor—We have talked about it. He has come up with a couple of fairly innovative ideas. He thought he might have a caravan and plug it into our electricity so he could watch the TV. Another time he suggested that he might rent a house around the block because that would be close enough for me to bring his dinner round. So he is thinking about it from time to time. Two of his friends have recently moved out into an apartment—two young women with Down syndrome—and they are part of a very small and hardly acknowledged pilot program in our area to provide support to people who have provided their own accommodation. They have moved into this rented apartment because their families have the means to pay the substantial rent, and they have a very interesting and attractive support package. Declan's response to hearing that they had moved out was: 'That's really good for them, but I'm not going yet.'

CHAIR—Where did the funding for their support package come from?

Mrs O'Connor—It is a state program—ADHC funded. We think it is very small. We think there might be 10 packages in our local planning area. We cannot find any information about it other than that we know a couple of people who are in it. That is very attractive. I imagine that they are perhaps keeping quiet because they need to protect themselves from the flood of inquiries that would come.

Senator BOYCE—A comment that has come up a lot is the inability to find out what is out there and even people who work full-time in the field not really being sure. Things like a central website have been suggested. How do people go about finding out things, and what do you think is the solution?

Mr Clarke—Word of mouth, just as Declan and Jill found out about the couple of people in their area. It is largely through word of mouth and informal networks.

Senator BOYCE—This was a point made yesterday: it is from other parents and other families. Yet, if you are socially isolated, as some of the families of people with disabilities are, it is not going to work that way either.

Mr Clarke—Exactly.

Mrs O'Connor—We still come across people—it is almost unbelievable; we are nearly in 2011—who do not know that they are entitled to a carers allowance.

CHAIR—We do that in WA too.

Mrs O'Connor—You wonder how people could not know that, but they do not. If they have not asked the question, they—

Senator BOYCE—Or they do not think of themselves as carers.

Mrs O'Connor—That is right, and that is another really big thinking shift that needs to happen for us as parents too. It is great to have this mindset: 'I am doing whatever I need to do. I am this child's or this adult's parent, and I will do whatever it takes.' We need to get people thinking that what they are doing is actually beyond parenting.

Senator CAROL BROWN—So how do we fix it? What do we need to do?

Mrs O'Connor—I think we need to make caring perhaps more valued. That is happening with things like the Carer Recognition Bill. We need to almost tell people sometimes what caring is, as opposed to parenting—parenting is those things that we do for all of our children, and caring is all the other things that we do for the person with a disability—and that it is okay to identify yourself as a carer and therefore make yourself eligible for the supports that are there. I think you have to recognise yourself and be comfortable with that as a carer before you would, say, ring Carers New South Wales to talk about what benefits and services might be available and to look for counselling through their excellent counselling service, for example. Many people do not think of those things, because they actually do not think of themselves as carers or they see it in some way as a pejorative term—a carer is somebody outside the family or perhaps even somebody who is paid to do it.

Senator CAROL BROWN—For those parents who do know of these services, we still hear that they cannot access them or that they know there are services there but they are not sure exactly what is available. What can we do to make it easier? You are highly engaged and you found out about this pilot program, but I am not sure if you know the name of it or who you had to contact.

Mrs O'Connor—No, I do not know the name of it, and I found out about it because I ran into the mother of one of the young women at the supermarket and she told me about it.

Senator BOYCE—It is not an ideal way to put out that information.

Senator CAROL BROWN—It is not the most effective and efficient way. I think we really need to take it to people and, as they get older, we really need to take it right to them, wherever they are. So we need to find the most effective means of doing that.

I guess the most common point of contact with government services is through benefits like disability support pensions or carers allowance. Maybe even putting print information out to people is still very important for people who are older. Many older people are very happy to use websites and online information, but some are not. We need to be talking to people personally, too. We need to provide opportunities for that. People can ring Down Syndrome NSW, for example, and talk to us, but they do not always think to do that.

So we need to have many different ways of engaging people so that we catch everybody who needs to know. It needs to be on the web. It needs to be in print. It needs to be in front of people on the end of the phone. It needs to be in lots of organisations. People will sometimes come to us with queries that are not particularly about Down syndrome but they come to us because their child has Down syndrome and we might know about something that is a bit more generic. At other times they will go to a more generic service like Carers NSW, for example, because they have identified that it is a caring issue. So the information needs to be in lots of different places and lots of different formats. I think a centralised website would be great, but it will not cut it for everybody—certainly not at this stage of their lives.

Senator BOYCE—FaHCSIA might well say that they do have that already, and so would the state department, I imagine.

Mrs O'Connor—There is a centralised website in the UK that I came across a few months ago. Obviously services are organised very differently there and there is more of an entitlement for everybody. But there are a couple of centralised accommodation websites where you can just go in and type in, 'Jill O'Connor; I live in the northern suburbs of Sydney; I have a 25-year-old who has Down syndrome; we would like him to live in a three-bedroom house within five kilometres of our home,' and up pops where the nearest vacancy is, so you just go for it.

Senator BOYCE—Wow!

Mrs O'Connor—I want one of those!

Senator BOYCE—Yes—it is like you actually have a right to move out!

Mr Clarke—There is perhaps some irony there in that I do not think either FaHCSIA or the ADEC website in New South Wales are particularly accessible websites. You might think they would be the leaders in accessibility, in terms of their client groups, but it is not so.

Senator BOYCE—I want to ask one last question around that idea of lifelong planning and planning for when you are no longer there. It requires sustainability, past the efforts of the parent to sustain it. Could either or both of you talk about what you have seen or what you have heard about in terms of developing sustainable plans?

Mrs O'Connor—Some families have been very good at developing sustainable plans within the family.

Senator BOYCE—So this relies on a sibling keeping the plan going, or something like that?

Mrs O'Connor—Absolutely, or a group of siblings. Outside of families, I am not aware of very many sustainable plans that do not involve supported accommodation. So it does fall largely to siblings, who may or may not wish to take on that role. The siblings themselves will be ageing along with the person with Down syndrome, and it is almost another generation after that that needs to be engaged as well.

Mr Clarke—Most of us do not like thinking or talking about what happens after we are gone, and families of children with disability are probably no better or worse than anyone else at thinking and talking about or planning for those issues.

Mrs O'Connor—We do talk to a number of families where siblings have taken over the care of somebody with Down syndrome, and that has not always been planned. Sometimes it has been. Very often we will hear from the partner of the sibling, for whom it was never part of the plan, and they may take it on willingly or they may take it on as an obligation. Very often they take it on, whether it is willingly or not, without very much preparation and with very little knowledge. They are most unlikely to know about services.

As parents, we are not very good at keeping records of what we have done. As the mother of a person with a disability, you are the boss of the game, you keep it all in your head and you keep it going. When you are not there, who knows what you have even tapped into, what has been explored before and what has not? That is something else that we should perhaps be talking to parents and families about—keeping better records, in whatever format, of what the person's needs are and how they are actually being met on a day-to-day basis rather than just letting mum take care of it so that, when mum is not there, nobody knows where to start and it all has to start over again.

CHAIR—Thank you very much for both your submission and your evidence. It is very much appreciated.

[9.47 am]

BIRT, Mr Edward Oliver Ross, National Disability Practitioner, Life Without Barriers

CHAIR—I welcome the representative from Life Without Barriers. I understand information on parliamentary privilege and the protection of witnesses and evidence has been provided to you.

Mr Birt—That is right.

CHAIR—We have the Life Without Barriers submission, No. 40. I invite you to make an opening statement and then we will ask you some questions.

Mr Birt—Life Without Barriers welcomes the inquiry into planning options for people ageing with a disability and, first of all, would like to state that we hold that the inquiry is directly related to the current Productivity Commission inquiry that is underway. There are obviously lots of synergies there. That inquiry is looking into long-term care and support for people with a disability. In relation to the recent input into this Senate inquiry from National Disability Services, we agree with the statement:

> Carers and people with disability cannot confidently plan for the future unless they have assured access to services and choice about service provision.

I think the reason we have so many concerns about people ageing with a disability, and particularly those living with ageing carers, is the limited availability of services to meet unmet need coupled with the uncertainty that exists about what is available, what you are eligible to receive, how to access services and so on. As a result of this uncertainty, I think it is fair to say carers who are able to do so have in many cases simply got on with things and done what the absence of an accessible support system has led them to do—that is, to provide the care and support for their sons and daughters themselves. Often these carers quietly get on with being caregivers, largely disappearing from view until such time as their own health, as a result of natural ageing, means that they are no longer able to provide the care and support they once did, and so a crisis ensues.

The support that family carers provide to their sons and daughters is incredible and deserves recognition and acknowledgement. But if you think about developmental models that focus on transitioning through important life stages then, as we know, people with and without disability who live at home perpetually with mum and dad often just do not have the important opportunities to effectively negotiate transitional life stages and neither do their parents. In many ways people remain essentially stuck in a childlike or adolescent life stage instead of developing the emotional, psychological, financial and functional skills to be as independent as they can be to make their way in the world without their parents and vice versa, for their parents to make their way in the world without their children.

This sector is well developed and capable of providing a lot of skills, knowledge and capacity to provide transitional support services for people with disability, but there are some systematic issues that will get in the way of that. I have some knowledge of planning in respite services for ageing parent carers through the support that Life Without Barriers provides but the problem can often be that obviously needed supports are just not available.

More accommodation support services are obviously needed. I know of a recent example of a man with autism and intellectual disability in his 50s with parents in their 80s, who were just not coping with physical and mental health, breaking down. He was bouncing around in respite for some 12 months, sometimes returning home for three or four days before going into respite for another week. After 12 months the carers relinquished his care, leaving him in respite and at this point he became a high priority for supported accommodation. Two months later a group home placement was identified for him and he has since moved into that home and is reported to be going from strength to strength, developing functional skills and enjoying the new living arrangements. Additionally and equally importantly, his parents, who as I said are in their 80s, have significantly improved stress levels and associated mental health issues, which were very apparent.

There is a great deal of depression and mental health issues in the population of older people with disability who reside at home with their parents. And, more broadly, older people with a disability do experience greater issues around mental health. Often parents are suffering mental health problems as well. Often this is due to isolation experienced by these family units. There has often not been the opportunity to develop independent living skills that only come with leaving the nest. A good example of this being in relation to sexuality and intimate relationships, as opportunities for relationships may be limited by residing with parents into old age, which I am sure we can all appreciate. As a result, many examples of unmet need in relation to sexuality and relationships are evident in this group.

Often there are limited or underdeveloped options available for day programs for older people with disability. The focus with those services is often on the younger age groups. If you are lucky, you may get two or three days a week but you may be thrown in with school leavers and expected to cope.

Many older parent carers are distrustful of government services and may not understand the ongoing costs of staffing, be it day services or supported accommodation models for people with significant impairments. I have frequently heard not just in my job at Life Without Barriers but previously as a manager of other non-government agencies the idea that if we just build more houses that would fix things, but the real cost obviously is the staffing. With the cost of a year’s staffing for a typical group home you could purchase a lovely four- or five-bedroom family home, which is why people get very frightened about the cost.

Relationships with families, particularly for older families, are critical. We are not presently as a service system effectively able to build relationships, as services are piecemeal and there is an absence of ongoing case management, which is something I hear time and again for families that are not in crisis mode.

It is also important to note the cultural issues that exist for Aboriginal parent carers of people with disability, who may themselves have been part of the stolen generation and be additionally traumatised and distrustful of the service system. Again, relationships are critically important here. A caseworker told me that she is often not able to complete an assessment with some of the older families she meets until she is some six to nine months into the relationship—she was working in a respite program for older parent carers—as they are often so distrustful of outside support. So I think that notion of ongoing relationships is really important. Often we leave people when everything is going well, but the relationship disappears and then off they go.

Active ageing is important, and often retirement planning options are not well developed for people ageing with disability. We know of many people in day services who really feel out of touch with the age range of the typical clients of these services, so more effort needs to go into making age-appropriate day service options for people ageing with disability.

There are also lots of great innovative services that are presently in operation providing all sorts of much-needed support to families. But I guess it is one thing to provide psychological and emotional support, arrange respite support and bring in some modifications and equipment to a family home to improve their living arrangements there—and those things are all very important—but you can argue that things are always needed and appreciated by families, and that would strengthen the capacity of the family to continue. But even these supports are few and far between and, again, often bandaid the larger problem. What the person and the family would really have benefited from is the expectation that, typically, somewhere between the ages of 18 and 30, as per the rest of the population, people with disability move out of the family home. This is not a given at the moment by any stretch of the imagination; rather it is the exception, not the rule. I am also conscious that retirement villages and things like that, where people do live with their sons or daughters with disability into advanced years, typically will not accept a younger person with a disability moving in, so that relationship has to end. There might be options there too.

To wrap it up, I think that these technologies, systems and capacities are there in the service system but that perhaps they do not hang together quite as they should at the moment. Some of the systemic issues that the Productivity Commission inquiry is also looking into include, certainly, individualised funding and support and making sure that a person with a disability is the client of the service system. There are also things around wills and estate planning and supported decision-making and other things that are relevant and important too.

Senator BOYCE—On the example you gave of the guy with autism and some intellectual disability, you said that the parents relinquished care. Did they make him a ward of the state or something like that?

Mr Birt—No, he was in his 50s. Effectively he was going in and out of respite options—this is in New South Wales. I have not met this gentleman myself; this is on the report of one of our care coordinators, case managers. There are just no accommodation options available, and essentially it would seem, in this instance, that the point of access to the supported accommodation system was when the parents were unable to take him back into the family home. I am sure he was probably on an accommodation waiting list but not able to access that accommodation until there was a total breakdown, I suppose, in that family unit. For mum and dad to say that they were unable to support him anymore—

Senator BOYCE—So basically they had to refuse to take him back home?

Mr Birt—Yes. I have seen that on a number of occasions throughout my career, not just with Life Without Barriers, where respite centres typically become blocked because that seems to be the point of access to accommodation support in a lot of instances. There are well-developed waiting list systems and registers.

Senator BOYCE—For supported accommodation, group homes and the like?

Mr Birt—Yes. I think it is just that there are not enough of them, typically. I remember sitting on a placement panel when I was a manager of JewishCare in the eastern suburbs in Sydney and we would have 100 people and there might be three or four places available. That was back in 2004 or 2005, but the unmet need is quite tremendous.

Senator BOYCE—So there is the unmet need of the people on the waiting list but there are also the people you have talked about who either do not know they should be on a waiting list, do not want to have anything to do with the system anymore or do not think there is any point in putting themselves on a waiting list.

Mr Birt—I think that is very true.

CHAIR—I want to ask about ‘waiting lists’ because our previous witnesses said there were no waiting lists. You talked about the JewishCare waiting list, so I want to make sure I understand what you were saying. Are there waiting lists for various organisations’ accommodation or are there government waiting lists?

Mr Birt—Perhaps they are not referred to as waiting lists. You would be on a register to say that you are eligible.

CHAIR—We have heard that.

Senator BOYCE—Victoria has a register too—they don’t have any waiting lists, just a register.

Mr Birt—An agency like Life Without Barriers or JewishCare might operate a supported accommodation facility that is funded by government in New South Wales or the Northern Territory or WA, but typically those placements are managed through a central register that the government will operate—for obvious reasons: that needs to be the intake and referral point.

CHAIR—Is the register a register for supported accommodation or is it a register for a package?

Mr Birt—What I was talking about there is for supported accommodation. There is much more flexibility around using support packages now, either for an alternative family placement or to support you in your own home, through the Leaving Care Program, for example, where you have quite a degree of flexibility in terms of how that funding package might be used.

CHAIR—In WA we do it differently. Each state does it differently.

Mr Birt—That is right.

CHAIR—In New South Wales you go on this register.

Mr Birt—Yes.

CHAIR—Once your name comes up, can you then choose a supported accommodation package? How does that work?

Mr Birt—It has been a while since I was involved in those processes, but you can refer to ADHC’s policy and procedures, I think they are called, on the way that accommodation places are managed. That is available through their web site. They do have prequalified providers. There are a lot of agencies that are prequalified as accommodation support providers around the state. Panels meet in the different local government areas periodically throughout the year to manage any vacancies that come up.

Senator CAROL BROWN—We did have some evidence about the intake and referral unit, but essentially that was seen as being a crisis accommodation mechanism.

CHAIR—The example you just gave was, in effect, crisis driven.

Mr Birt—Yes.

Senator BOYCE—You have talked about services in New England and the Hunter region. Is that basically where Life Without Barriers operates?

Mr Birt—No, we are all around the country, but our principal areas of operation are the Hunter, New England, the Illawarra and Shoalhaven, western New South Wales, Broken Hill and Queensland. We operate group homes and HACC services throughout Queensland and, in fact, all the states and territories. We do not really have any disability funding for services in the ACT, but that is the only state or territory where we do not. We operate respite, supported accommodation and alternative family care options. That is like a foster care model but for adults, where you have screened, assessed and trained alternative family placement. We have community access and participation services. We have day services, which is in fact how Life Without Barriers started out initially, as a day service provider in Newcastle.

Senator BOYCE—Perhaps you could give us a sense of the difference between regional and urban areas and the services available. Are there any extra problems?

Mr Birt—Absolutely. I think that transportation is something that always comes up for people as a huge additional expense. There is also the lack of access to specialist services in regional and remote communities, and also there are cultural issues associated with planning respite and things like that. In certain locations you can expect to send out a letter to say, ‘Sign off on the days that your son or daughter will come into respite.’ It is all very clear and identified in an Anglo-oriented fashion, but in more regional and remote communities that is not an effective way of managing those, so it is more local committees that get together and plan the allocation of respite hours.

To be honest—I was just speaking with somebody yesterday in a remote location—there is always a sense that things are worse or more difficult in the bush or in more remote locations, and I am sure that in many regards they are. There are a lot of families that we just do not know about who are living in remote locations. They are much less likely to not be identified if they are living in the cities, but really I think that a lot of the issues are the same. The access to services, particularly supported accommodation services, is not great anywhere around the country.

Senator BOYCE—We are looking at long-term planning here and what we might do to make it easier. Is the lack of services an issue in terms of planning?

Mr Birt—Yes. If you think about a system like person-centred planning, which is something that is talked about a lot at the moment in disability services, where the person’s goals and aspirations are at the centre of what you are doing, their vision for what their life might look like is the driving force behind what we do, and every disability service standard around the country would say that is absolutely right: individual needs, decision making and choice, service access, valued status—the list goes on. They are all wonderful things. The legislation has it absolutely right, but I think that lack of funding and service options is a big problem.

Something that I think the Productivity Commission inquiry would be interested in is the control of planning to ensure that people are directing services and not just fitting into a pre-determined program. For any service type, be it a group home, a day service or a program within that day service, everything has a shelf life—for every human being. Typically in a share house accommodation arrangement you would think a group of adults living together would last without a change of at least one member of that unit between six months and 16 years—and I am just making that up. But we need that flexibility in the models to be really person-centred and say: ‘This is not working. The person does not get along with Jack or Jill. We thought they would, but it is not working out.’ Instead, we might bring in the psychologist or the clinician to develop a positive behaviour support plan to—

Senator BOYCE—Which is not what would happen in the real world.

CHAIR—They would move out.

Mr Birt—A lot of this stuff needs to come back to simple human—

Senator BOYCE—Yes.

Mr Birt—But, without the capacity I suppose in the system, people do hold very much to what they get. I read in one of the *Hansards* I think Sue talking about the squeaky wheel. People who do get into difficulty and are supported are very keen to hold on to whatever they get. It is difficult to have those conversations with mum and dad around perhaps changing a support model and other issues because they are very well aware of how difficult it was to get that support in the first place and they are not about to give it up lightly. It is not a system with any fat in it, so people are very much hanging on to whatever they have got.

CHAIR—Or attempt to change it just in case they lose it.

Senator BOYCE—Yes, because you might lose it.

Senator CAROL BROWN—There are many people, as you indicated earlier, who are not accessing any services, so there is that unmet need. You talked about people not accessing services because, firstly, they may not know they are out there or, secondly, they do not trust government. I was interested in your recommendation 9.1 about making every effort to identify families. I wonder whether you have any suggestions or measures that you would like to put forward to the committee to be able to do that.

Mr Birt—It is one thing to identify, but it is about active case management I think. That is the only way to sort of describe it. It is that ongoing relationship with the family. We are seeing, for example, in New England with our Respite for Older Carers programs, which have been operating for two or three years now, other families come out of the woodwork when they hear about the service, about the outcomes that sons or daughters experienced, about the outcomes for the family and about the staff. A lot of it is to do with the quality of the staff. A lot of families do not want a young, bright-eyed and bushy-tailed person who is going to come in and cause havoc. They want somebody they can trust and develop a relationship with over time and see some outcomes occurring. Actions speak louder than words.

The thing there is that there is such churn in the sector for staffing. It is appalling for families to have to tell their story again and again. We have to identify them, but we have to have the support for them when we are doing that. It is not enough to make another empty promise or suggestion.

I reflect on my work in the early part of the decade when I was a service access system planner with DADHC. I do not know if people recall that, but it was a system where DADHC identified families in crisis and we basically operated more or less as consultants, so we were independent of government but we were not the service provider either. It was a quite interesting arrangement. We did service planning with families. We got it all down and developed support plans for these families in crisis and then we basically handed that plan back to government. I thought there was something interesting in that because of the independence of it.

Senator BOYCE—Except it needs services at the end of it, doesn’t it?

CHAIR—Exactly, otherwise you just disillusion people.

Mr Birt—I thought that was quite interesting. Certainly, there is a need for active case management and ongoing relationships. If people are born with or acquire a disability that means they will have significant ongoing support needs over the course of their lifetime, why would that relationship ever end with the funding provider? I think it often slips away when people are going okay or when a respite service is engaged, for example—though they are onto it now; there is some sort of handing across—because that might be a short-term arrangement.

Senator BOYCE—One service does not cover every facet of what should be a full life, so to speak. You talked about moving out of home between 18 and 30 as being the exception rather than the rule in this community. What sorts of supports would be needed to make it the norm?

Mr Birt—I think there is a lot of expertise both in government and in non-government around functional skill development, active support and ways of building transitional planning into people lives. If you start with that expectation that people will move to a different arrangement, a lot of people will need to live with others because of their support needs. But, again, it is about the expectation and the transitional support units. Often mum and dad cannot teach the skills that are needed. They could not teach any of us because we treated them as mum and dad. They say, ‘We went home and mum did the laundry’—sorry to be sexist like that, but often it is the way. It is very difficult for people to learn those skills until they move out of home. They might stuff up their finances, not eat particularly for a week or leave the house a pigsty so the girlfriend will not come over. People actively learn through living.

I was thinking of a person I met who accesses our day services in Batemans Bay. He does a lot of chores around the day services and his mum cannot believe it because he will not do that at home. Even though she is aware that he can do it and he knows that she knows he can do it, it does not matter because at home he does not do it. It is a funny thing. Families can only do so much. They can be part of those skill development programs, but they need the right supports and they need transitional living units—like share-house accommodation—so people can try living in the community. It might involve a six- to 12-month lease and there might be a tailored skill development program that focuses on their independent living skills. From there, you can then see where things go. A lot of people surprise us in terms of the level of independence that can be achieved. But other people who might seem to have good functional skills need a lot more support in the community for various reasons. Making sure that extended family networks are part of that planning process is important. Critical to person-centred planning is that the person is not doing it alone. Getting people involved as appropriate is important. Intimate relationships is a good example of where we need to enhance our skills to support people around the issues involved there.

Senator BOYCE—But there were government rules and regulations which would have prevented that in some areas.

Mr Birt—Absolutely.

Senator CAROL BROWN—In various submissions we heard of parents near the end of their lives making preparations for their children to be looked after and identifying a relative or another person to continue accessing services for their children after they have gone. Do you know of that happening in the area where you work? Can you talk further about support for more formalised planning around that sort of structure?

Mr Birt—I must say I am not that aware of examples of where people who are nearing the end of their lives engaging other people in the planning processes. Having said that, I guess I am aware where families may have done that, though they have not called it that, where they have involved brothers and sisters in the planning processes. I cannot give you any clear examples of where I am conscious of that happening, although I am sure it is happening. What was the second part of your question?

Senator CAROL BROWN—That sort of structure where a formal plan is made for the child after the parents have gone and services and support are built into that planning.

Mr Birt—I think that a lot of the time those arrangements, I suppose, outlive the parents or carers if somebody has a government funding package. Then, of course, if you are aware that mum and dad can no longer contribute to that planning process then it is—

Senator CAROL BROWN—So essentially, if mum and dad do not identify a relative or have not made any other plans, they have a conversation with the service provider about what will happen after—

Mr Birt—Yes. There are certain things that we do in terms of where we identify that the person has a limited support network. Then we engage a funded advocacy service. In some instances, yes, it might be a brother or a sister. We certainly make referrals to guardianship and administration boards around the country.

Senator CAROL BROWN—You talked about your example about the elderly parents going through that process—I think you said it was over 12 months, which would be very stressful. It is to eliminate that. They are no longer able to care for their son, and there are support mechanisms there to sit down and talk about a proper planning process without their son having to get to a crisis point.

Mr Birt—I think it was well identified that this was a crisis point. Often people can identify the unmet need but cannot do anything about it. I think that perhaps workers in the sector are used to that, in a way. In that instance, there would have been information back and forth between the care coordinator and ADHC as the referring agency, and I am sure people were doing their best to identify what options there were for alternative accommodation. I am not sure if that answers the question.

Senator CAROL BROWN—We need to do it better, obviously. We should not have to have a 12-month process where very elderly parents are under extreme stress. Nobody wants to give up their child in the terms that you have spoken about, but—

Mr Birt—Absolutely. I think planning gives people some sense of sanity, literally, and of moving forward: ‘Okay, things are terrible now, but this person’s given me this goal of sourcing alternative accommodation.’ How we are going to do that is through talking to the intake and referral officer at ADHC and looking at what is available on the register et cetera. It gives people concrete steps with time frames and who is going to be doing it. So I think it can keep people together, but often people may be reluctant to put a plan like that into place. We will go through those processes, but we are not going to make any promises, because we do not know what is available, how to access it and when it might be forthcoming. But, if you are trying to say that a plan would strengthen the case, I think that is certainly true. In that instance, if a documented plan had been put forward to the funding agency around exactly what was required or something like that—

Senator CAROL BROWN—But that would be for that sort of project, wouldn’t it, rather than a long-term plan that is going to—

Mr Birt—True. With a lot of the older parent carers with older children with disabilities, I do hope we can do things differently. We need to support those people at that time in their life. I am trying to think of what has changed in terms of long-term solutions for people at the moment.

Senator BOYCE—I have a couple more questions. With the ‘key person’ you are talking about here, who is a key person, generally, and how does a key person become a key person?

Mr Birt—In terms of plan development?

Senator BOYCE—Yes.

Mr Birt—At Life Without Barriers, we have coordinators of support. They act like a case manager. For our specific service types, they will be a key person around the person’s individual plan. As a funded service, everywhere we operate we have to have individual person-centred plans for all of our clients in all of our service types.

Senator BOYCE—To show to the government and whatever?

Mr Birt—Yes. Unless the person is in supported accommodated—where you have more extensive access to them, their life and their needs—they are typically plans that are specific to the service. ‘I would like to have respite that weekend. While I am at respite, I would not mind learning how to use an ATM or going to a particular activity.’ They are specific activities, not whole of life.

Senator BOYCE—It is short term, yes. Does Life Without Barriers strike the situation of parents and carers saying to you, ‘How on earth can I get organised so that I can be confident that Harry is going to be okay when I am no longer here?

Mr Birt—Yes, we do and typically we refer the person back to government. Unless they are an existing client of ours in a more whole-of-life service like a supported accommodation service or where we drop into the person’s home to provide them with support then we are more likely to get involved and do some of that planning with the person. They have to be already engaged in a fairly significant service type.

Senator BOYCE—So you do some of that sort of planning with people?

Mr Birt—Yes.

Senator BOYCE—Can you give us a quick snapshot?

Mr Birt—Essentially, the person will have a detailed file with the important information about contacts, the nature their diagnosis and how that impacts on them, mobility support requirements and nutrition and swallowing requirements et cetera. That is all the background material that helps provide the support to meet their individual needs. Importantly, when it comes to the person-centred planning process, the onus is on understanding the person’s goals and aspirations. Which way do they want to go with our services? Firstly, do they want to receive a service from Life Without Barriers? That is always the first question that we ask. If they do not, it is an opportunity to understand what is not right, whether we can fix it or are there grounds for requesting a transition to somebody else. The individual planning process is a 12-month cycle, but it might include long-term goals as well. But we hinge things back to the person’s goals and aspirations—if they want to take a holiday to Hawaii, for example. There are lots of things in that holiday to do with financial planning and budgeting and to do with anxiety management associated perhaps with taking a flight overseas. There are lots of opportunities within person-centred goals for functional skill development for clinical outcomes and for personal outcomes—satisfaction and that sort of thing.

Senator BOYCE—That is still about building life skills?

Mr Birt—Yes. We will have a plan that behind the scenes is fairly nuts and bolts. It will have the person's goals as well as objectives and so forth as to how those goals will be met. But the person will see and understand their goals as things that they have come up with with the support of their family and friends. One of the key benchmark indicators for quality around those plans is the engagement of people important in that person's life. If we have a meeting around a person-centred plan and Johnny, our client, is in the room and it is just him and us, we have to think: this is really not good enough. Johnny might have expressly said: 'I only want to deal with you. This is the way I want it. It is nobody else's business.' In that case, with Johnny's support, we might have to manage those difficult conversations with others around why that might be the case.

But typically a benchmark indicator of quality is engagement. We are always looking at expanding people's relationship networks, fundamentally. We might take Johnny's statements that year, but we will always be looking for opportunities. It might be that he is interested in Aboriginal artwork or, as I said, the holiday. There are always opportunities for expanding networks: sport and the rest of it.

Senator BOYCE—This is my last question. You mentioned before some of the cultural aspects of working with Aboriginal clients. I think you are the first group we have come across who have told us that they do have Aboriginal clients with a disability. Could you tell us a little bit more, please.

Mr Birt—We have a lot of instances where we have taken on services and come across people with Aboriginal heritage who have been disconnected from that heritage. We always work to understand the person's country, where they are from and their language group, and we build that into cultural care planning. In the same way, if somebody identifies as being of a particular faith or cultural background, we try to partner with people who will understand that need. So we try to recruit and retain Aboriginal staff. There is an instance of a lady in Cairns—I just learned about her—who has been in supported accommodation for about 20 years in a service that we have taken on. She has very limited verbal communication—a lot of swearing in English, for example, is what she engages in—but a few weeks back, when she met a woman from her country, some nine hours west on the gulf, she understood every word when she spoke in her own language.

Senator BOYCE—Even though she possibly had not heard it for 20 years.

Mr Birt—Absolutely, yes. So I think people are isolated and cut off, and it is a bit of a journey, I suppose. If somebody identifies as Aboriginal or you understand them to be Aboriginal then it is part of your duty as a care provider to try and understand what that might mean for the person and try to explore that, because fundamentally that will be in the best interests of their health, wellbeing and quality of life. Along the way, if there is no connection or there is no sense of belonging, I think it is great anyway. That is the bottom line. People enjoy cultural experiences. I am saying that particularly for clients with complex or limited communication. We try to expose people to opportunities as well, I suppose, in those instances. But we do have cultural care planning for people with disability.

CHAIR—We have run over time, so we are going to have to call it to a close. Thank you very much. I do not think we gave you any homework, did we?

Senator BOYCE—I do not think so.

CHAIR—Thank you very much. Both your submission and your evidence today are very much appreciated.

Proceedings suspended from 10.33 am to 10.45 am

BLASZCZYK, Mr Michael John, Chief Executive Officer, McCall Gardens Community Ltd

HAGGETT, Ms Rachael Mary, Parent Advocate, Futures Alliance

HAYHOE, Ms Nicola, Research Officer, Futures Alliance and Ability Options

HEWITT, Ms Jo-Anne, Chairperson, Futures Alliance

McNAMARA, Mr Edward, Manager, Planning and Government Relations, UnitingCare Ageing NSW.ACT

CHAIR—Welcome. I understand that you have been given information on parliamentary privilege and the protection of witnesses and evidence. We do have some reminders if you need that.

We have your submission and have numbered it No. 16. What I intend to do is invite one or all of you to make an opening statement. There are a number of you and we would obviously like to hear from all of you but we have only a certain amount of time available to do that, so we will need you to keep your answers succinct, if that is okay, in order to manage that time.

Ms Hewitt—I have been nominated to give the opening address and, as each of the panel members brings a different area of expertise, we will play it by ear as to who will answer your questions.

The Futures Alliance was formed in recognition that current policy and practice in both disability and aged-care arenas fall short of the required response for people with a disability who are ageing. We are a cooperative of community representatives from the disability sector and aged care providers, and our alliance includes people with a disability and family members as well as academics and peak bodies. Our stated purpose is to remove boundaries and maximise community resources to deliver improved options for people with a disability who are ageing. We recognise that, since we have put in a submission, there has been an announcement about the disaggregation of the HACC program, and that will certainly have implications for people with a disability who are ageing. We are currently looking at that, although no detail about the policy has been released and—

CHAIR—It is so good that we do not have that yet!

Ms Hewitt—Exactly. So we are in the process of looking at how our blueprint sits with that and what kinds of recommendations we might make about it. We are keen to ensure that there is a seamless and flexible approach to service delivery and that we do not have cost avoidance and cost-shifting, which has happened in the past. It could be better under the new arrangement or it could be a lot worse. So we are very keen to ensure that people with a disability do not continue to fall through the cracks as they age.

We have presented to you what we call our blueprint on ageing with a disability. This came about after a conversation that we had with Bill Shorten about this time last year in his capacity as Parliamentary Secretary for Disabilities and Carers. We went to see him to highlight the issues that we saw for people with a disability who were ageing. He said to us: ‘Lots of people come and talk to me about this. What I actually need is a document that says this is what you should do.’ So we set about consulting with our members and with people with disabilities and their carers and came up with this document.

Basically we are calling for some genuine consultation with people with a disability as they age about what their aged-care needs will be. We need to recognise that people with a disability and their carers have often not expected to grow old, whether that was because of their physical disability—meaning, they had a short life expectancy—or because their intellectual or mental illness decreased their capacity to understand the implications of getting older. People with a disability need informed choices now as they are growing older in increasing numbers.

We support self-directed funding options and understand that in some states those options are already in place and are flexible enough to meet people’s needs. We are hopeful that on Friday there will be an announcement in New South Wales about some increase in flexible and self-directed funding options. We understand that Kristina Keneally is about to make an announcement about Stronger Together, too, so we are very hopeful about that.

We have called for recognition as a special needs group within aged care funding and legislation. We are not calling for people with a disability to have special access to residential aged care. That is not what we see as an option, although for some people that is very much an option. Rather, we would see that people with a disability would be recognised in the same way as other special interest groups, such as Aboriginal people, who age earlier than the general population and therefore require access to the support they need—for instance, access to Commonwealth aged-care programs and health and allied geriatric expertise. We appreciate that the assessment tools for people with a disability need to be different. The current aged care assessment tools do not really take into consideration the existing disabilities of a person and how that in fact changes over time or understand that we as disability providers need to be better at describing what constitutes a person’s disability and then what constitutes their changes due to an ageing process.

We are very keen to see that there is flexibility and collaboration between all levels of government and to avoid the claims of double-dipping. Currently, if someone has a disability funding package and then ageism requires supplementary services from the aged care system, they are unable to access those services if they already have a disability package, which may well have fallen short of their ageing needs. We are obviously keen to see that change. We want to look at some examples of good practice. Several years ago there was an innovative ‘pool’ pilot program that enabled people who were receiving disability services under the state to access some of the Commonwealth packages. We have certainly experienced among our group some good examples of good practice and good outcomes under that pilot program for people with a disability as they age.

We want to see professional development of the workforce in both the aged-care and disability sectors to be able to address the needs of this population. We also want to see consistency between the disability and aged-care standards to ensure human rights and accountability. There are aspects of those standards that are similar. But they are different enough to cause a problem for this group. I will close there and invite questions or comments. That is basically what we are here for.

Senator BOYCE—How long has the Futures Alliances existed?

Ms Hewitt—We convened in February last year. It came about from some discussions that UnitedCare Ageing as an aged-care provider were having with McCall Gardens as a disability provider about how to address the ageing needs of some of the population that lived in McCall Gardens. There was not an easy answer that fitted with the issues of each sector, as well as some of the legislative issues. So we started to have some conversations. We have been talking about this for 10 years. We have been on various committees and various groups talking about this. So we got together to produce some real action. We gathered some people around us and then it grew from there.

Senator BOYCE—Looking through your list of members, is there a defining link?

Ms Hewitt—When we first started it was a few of us who knew each other across the sectors. As we have grown, we have grown via invitation and people approaching us. A number of academics have come to us and said, ‘This is my area of expertise, so can I be part of it?’ We ensured that there were people from different sectors as well as representation from consumers. We have kept it deliberately small so that we can maintain the passion and commitment of all the members, but we have recently opened up to subscriptions and have started up a blog and a Facebook page, along with newsletters so that we can get the information out to other people. We also have a number of members from disability and aged-care organisations who follow us and contribute to the work of the Futures Alliance.

Senator BOYCE—Are you aware of any other groups doing similar work?

Ms Hewitt—Not specifically targeting this issue. We are aware of and have all contributed to various sector responses. National Disability Services, for example, have a committee on ageing and some of our members sit on that committee. But we are targeting that particular issue. So our sole purpose, even though we have other hats in our professional lives, for the Futures Alliance is around seeking better futures for people with a disability who are ageing.

Senator BOYCE—You spoke about examples of good practice in providing services for people with a disability who are ageing. Could you give us a couple of those, please?

Ms Hewitt—I might leave that to some other members of our group.

Ms Hayhoe—The age and disability care interface pilot was a Commonwealth initiative in which people who were living in 24-hour accommodation settings were able to access small packages of support that they were unable to access otherwise. Those packages were administered by an aged-care provider, UnitedCare Ageing, which assessed people’s needs, developed care plans, provided access to allied health services to address specific issues that people were experiencing and provided a small amount of additional resources to enable people to continue to engage in community based activities. The outcomes for a lot of people in that pilot, which has ended, were that they were able either to continue working or find alternative day program activities to continue to engage in their community. They also improved their mobility so as to participate as independently as possible.

Senator BOYCE—Is that continuing for those people or has that program finished?

Ms Hayhoe—It has been grandfathered, so the people in the program continue to get assistance, but the pilot had ended.

Senator BOYCE—Are you aware of any—

Ms Hayhoe—No.

Mr Blaszczyk—To add to that, during the life of the program—and it is still continuing—we have had no admissions to residential aged care as a result of those extra supports going in, so people have been able to age in place.

Senator BOYCE—In supported accommodation.

Mr Blaszczyk—In a supported accommodation arrangement. For those people requiring end of life care and palliative care, we have also been able to deliver that with help from those other experts in the community. It has been a great bonus for us and for our clients.

Ms Hayhoe—It was also a really good example of aged-care and disability care providers being able to work in partnership. This provided skills and experience in aged care to those who are used to supporting people with disabilities. That was really valuable.

Ms Hewitt—Talking to some of the other providers of disability services, there has been a flow on effect for other clients of theirs who are ageing. So it has been grandfathered for the particular people who were part of that pilot. But for others, it has meant that the staff in that disability service have had a level of training to recognise early signs of ageing. They can now recognise what is happening for that person if, for example, they are falling or incontinence is starting to develop. Those are ageing signs. They now know what to do to address those. Previously, that might not have occurred. Other organisations that we talk to that have not had access to that kind of support and training find that their staff are floundering and people are often not recognising the signs until far too late and they are not able to support their resident anymore.

Senator CAROL BROWN—Can we get some more information on how long that pilot program went for and how many participants there were?

Mr McNamara—Yes. There is an evaluation that you can get.

Senator BOYCE—Is it still being evaluated?

Mr McNamara—No. The evaluation is finalised.

Senator BOYCE—Yet from what you were saying, Mr Blaszczyk, it should still be being evaluated?

Mr Blaszczyk—I think that the program should have continued.

Ms Hewitt—Yes, there are still effects from it occurring.

Mr McNamara—It has been difficult to find out precisely why it was discontinued.

Ms Hewitt—We have asked that question. Basically, the pilot ran its course and stopped. The plane never landed.

Mr McNamara—The simple notion was that somebody with a disability in an accommodation support service should not automatically default into residential aged care as their needs increase while they age. They should be able to access community care packages or the like, just like any older person in the community can. That was the ageing in place notion of it. It is a lose-lose if the person is put directly into aged care. One of the things that it was hoped that the pilot would do was tease out more effective assessment mechanisms to be able to untangle, if you like, what the pre-existing support needs are and what the additional needs related to aged care are.

Senator CAROL BROWN—What was the age range of the people who participated in the pilot?

Ms Hayhoe—The people in Ability Options had an average age of 60 years. There were up to 10 individuals. The age range was from 45 to 83.

Senator BOYCE—And what was the range of disabilities?

Ms Hayhoe—It was primarily people with an intellectual disability, but there were some with dual diagnoses, such as epilepsy, mental health issues such as schizophrenia and a whole range of physical disabilities as well.

Ms Hewitt—Other organisations, such as the Spastic Centre, were involved in that pilot as well. So there were people with cerebral palsy and those with and without intellectual disability.

Senator BOYCE—We have had evidence in Victoria, particularly yesterday, suggesting that the ageing and disability workforces need to have overlapping skills. I am presuming that this is something that you have thought about.

Ms Hewitt—Absolutely.

Senator BOYCE—How would it happen? What would it look like?

Ms Hewitt—At the moment, it is fairly compartmentalised. People working in a disability service will get whatever training that they get, which is variable. Some people will have the minimum entry of a certificate III in disabilities, but other organisations do not necessarily follow that. Aged-care training is a whole separate package of training. There are some commonalities, clearly, but there are difference standards and different focuses on outcomes. Disability services are much more focused on community participation outcomes, whereas aged-care training is more focused on care and support and meeting someone’s health and medical needs. Obviously, with a person with a disability who is ageing there is a need for both. A person with a disability does not necessarily have the social contacts or the social ability, so there still has to very much be a focus on those community participation and social support elements. But in addition disability workers need that health and ageing focus on a person's changing medical and physical needs. Likewise, a person who has an ageing qualification needs to know that when they are working with a person with a disability that person will not necessarily come with the same abilities or connections socially that a person without a disability has.

Senator BOYCE—Is it as simple as another certificate?

Ms Hewitt—Perhaps. That would be a good start.

Mr Blaszczyk—Within the pilot program, what really worked for us—and I am guessing that it was the same for you, Nicola—was that coaching role that we had for the aged-care provider. The clinical nurse specialist came out and worked with it on the care planning with the other healthcare professional. That is where we made major leaps and bounds in terms of developing our own skills and competencies.

Ms Hayhoe—They provided specialist training to the support staff in terms of meeting the needs of that person.

Mr Blaszczyk—Yes. It was about the individual, wasn't it?

Ms Hayhoe—Yes.

Mr Blaszczyk—That really helped us.

Ms Hayhoe—We are also looking at specific aged-care training in terms of being able to better meet the needs of people experiencing age related changes. Through a registered training organisation, we are looking at targeted packages that we can provide to staff who are working with people with a disability.

Senator BOYCE—So you would send staff who currently work in your organisation, which provides supported accommodation, to do an aged care—

Ms Hayhoe—We would tailor some training and have that run within the organisation.

Senator BOYCE—What about the other way round—disability awareness training in aged-care facilities? Is that something that is being looked at or done?

Mr McNamara—No, I do not think that it is being done in any specific or detailed way. The approach towards aged care is that we are starting to learn a bit from the approach to disability support—things like empowerment and encouraging independence and so on. That is a movement that has happened more in aged care in the last five to 10 years. It is gaining more momentum. But I am not aware of any specific training happening for aged-care providers to manage people with a disability. There is residential aged care and there is community aged care. Most people getting aged-care support are still at home or are in community care services. It is just that residential care has become the fallback or the safety net. Most people have carers—

live-in carers such as spouses, for example. Nearly half of people on packages finish up in residential care anyway. Residential care is there as a very important safety net in the equation.

There was a recent example in Uniting Care of a man in his 40s whose mother is ageing. She had an incident where she had to go to hospital. She can no longer care for him. His only option is to come into residential aged care. There has been no planning to cater for that eventuality. That is part of this inquiry as well. That is another population: the group who are not currently in accommodation support or getting disability supports. Without their parents or that ageing carer in the equation, the fallback that is often used is residential aged care, because there are no places in disability accommodation support services vacant waiting for people in that situation.

CHAIR—So the option for that particular gentleman is residential aged care not because he is ageing but because there is nowhere else.

Mr McNamara—Yes, because his mother is ageing. There is nowhere else together.

Ms Hayhoe—There are also examples of people living fairly independently with maybe some support from families or who are living on their own with access to HACC in home support services who end up having a fall and are ending up in hospital. There are no appropriate community based accommodation for those people, and so they end up in residential aged care.

CHAIR—So while we are trying to get young people out of nursing homes, we are busily putting more in.

Ms Hayhoe—Absolutely.

Ms Hewitt—The experience that we had with this gentleman is that there were no vacancies in the young people in residential care program. He was offered 12 hours a month support to assist him to access care packages.

CHAIR—From where?

Ms Hewitt—From YPIRAC—Younger People in Residential Aged Care. He was offered 12 hours a month. We are currently making some representations to the minister about this situation. But he is currently living in an extended respite placement in aged care. We keep getting the response back that there is nothing.

Mr McNamara—A case-by-case thing happens. Would we train all the staff in that facility in case somebody with a disability comes along? It does not work that way. They come along, we admit them and support them because there is not other option for them. But people like that tend to take up a lot more resources than the general aged-care resident would. We do not see it as an appropriate option, but there is no other option.

CHAIR—It is crisis driven. We have had evidence this morning about the crisis driven system. It seems to me that this is more of that.

Senator BOYCE—What about funding for that person? How is that handled?

Mr McNamara—The funding would come through the basic funding instrument for aged care, the ACFI.

Senator BOYCE—So he qualifies for ACFI?

Mr McNamara—Yes. We cannot admit him unless he gets an ACAT assessment. ACAT have reached the point where they cannot find any other option; they have no alternative.

Senator BOYCE—But to assess him, so to speak.

Mr McNamara—They have no alternative but to assess him and refer him. When they refer him, we have to provide for him. We cannot say, ‘Go away; we won’t do it.’ We have accepted it, albeit on respite at this stage. The only funding that would apply in aged care would be funding through the aged-care funding instrument.

CHAIR—We heard evidence this morning of another person being rejected from ACAT assessment because that person was not 60. It seems to be—

Ms Hewitt—That varies from region to region.

CHAIR—Exactly. There are differences between regions about whether an ACAT team will assess or draw the line and say, ‘You’re not 60 so you’re not in.’

Mr McNamara—This ACAT held the line very staunchly but reached the point where they had no—

CHAIR—What else could they do?

Mr McNamara—Yes. It was not fair to the parents or anyone else.

Ms Hewitt—They were also dealing with the parents at the other end, who did not have the capacity to continue.

CHAIR—So this is absolutely the last resort.

Mr McNamara—There is no age limit, as I am sure that you know, is the Aged Care Act or the Disability Services Act, for that matter. But there are target age ranges for planning purposes and for—

Senator BOYCE—But they have almost become laws, so to speak.

Mr McNamara—Some people use them that way, yes.

CHAIR—We keep coming up against this barrier between disability services and aged care, with the first being a state responsibility and the second being a federal one.

Senator CAROL BROWN—If it reached a crisis point and the ACAT team assessed him, it was a crisis point when he was trying to access disability supported accommodation.

Mr McNamara—Yes. He had been offered some, but it was not sufficient to support him at home without his mother’s support, and she was unable to provide that now.

Senator BOYCE—Supported accommodation was not available?

Mr McNamara—No.

Ms Haggett—There is not any supported accommodation. That is my interest in this. There is no supported accommodation.

Mr McNamara—He could get some HACC or even a community aged-care package. But it would not be sufficient without his mother’s support because of his high needs.

CHAIR—He did not have anywhere to live.

Mr Blaszczyk—We were having coffee earlier and talking about numbers. One of the things in terms of unmet need and that crisis approach is that we do not know what the numbers are. We have no idea of the size of the issue.

CHAIR—That has become evident this morning.

Ms Haggett—On the way here, I bumped into a friend of mine who is a retired GP and told him what I was doing. He said that you should ask GPs. Every GP has lots of families with ageing carers of people with a disability who are ageing. He said: ‘Why don’t you just send round a survey to all GPS? You’d soon get an answer.’ He said that that is partly why he left—because he could find nothing for these families. It is a huge unmet need that is going to explode.

Senator BOYCE—The AMA and the GP colleges were on our list of people who were invited to submit.

Ms Haggett—He thought that that would be a quick way. He said that in his experience people would be very willing to fill in any data.

Senator BOYCE—Victoria suggested that what we needed was basically a national register of ageing parents of people with disabilities. I can see from all the nodding going on that that is considered to be a good idea.

Ms Haggett—You sort of fall off the radar once your person with a disability turns 18, it feels like. From then on, you are on your own, pretty well.

CHAIR—We plan it okay up until then. As soon as they are out of school—and they use the able bodied school limit—you fall out of that system. Then you are on your own.

Ms Haggett—Then it is piecemeal. You get what you get. If you are active and stroppy, you get a lot. If you are quiet and do not speak English you do not get anything.

CHAIR—I have noticed that.

Ms Haggett—I am active, and I get a fair bit.

CHAIR—That is my experience around Australia, I have to say.

Senator BOYCE—We were referring to it as the squeaky wheel.

CHAIR—But active and stroppy is fine.

Ms Haggett—For instance, I know about weekend activity programs—my son goes to several of them—but if you were quiet and did not speak much English you would not even know they were there. It is very inequitable in that way. No-one sits down and says, ‘What does your person need in order to have a good life?’

Ms Hewitt—People end up in situations where they have to abandon their adult child in order to get support.

Senator BOYCE—We heard a story this morning of a guy who spent 12 months bouncing in and out of respite care until his parents relinquished him.

Ms Haggett—And the cost of that is huge.

Senator BOYCE—The parents were in their mid-80s, mind you.

Ms Hewitt—Of course, what ends up happening is that people then are overserviced. It is a much more expensive option to have someone in 24-hour care who may or may not need that. The fellow we are talking about certainly does need access to 24-hour care but does not necessarily need someone there 24 hours a day; he needs to be able to press his button—albeit that he probably would use his foot to do that because he does not have use of his hands—and know that somebody is going to come to assist him if he needs to set up in bed or whatever needs to happen. He does not need someone there 24 hours a day, but he is taking up a residential aged-care bed and lots of people are taking up group home beds who need access and drop-in support but do not get it.

CHAIR—If there had been long-term planning for that particular person, those processes could have been set in place so he could at some stage have transitioned into that.

Ms Hewitt—And those people being relinquished by their families end up in 24-hour respite and, consequently, 24-hour supported accommodation, whereas with some good planning and good structures in place they may well not have required that level of care in the first place.

Senator BOYCE—That brings me back to the blueprint. Would you talk about how you use the blueprint, who knows about it and what its purpose is.

Ms Hewitt—We have been pretty active in sending it to both government representatives and policymakers. We have sent it to every department that it is worth sending it to, both state and federal—of course, we operate in New South Wales, so that is our context. We have sent it to the

Department of Ageing, Disability and Home Care and the New South Wales Department of Health. Federally, we are meeting with Jan McLucas next week and with the opposition spokesman on disabilities in New South Wales this week. We are very active in distributing this.

Throughout this year, we have also been speaking at various sector conferences, including the gerontology conference a couple of weeks ago and the National Disability Services conference. We have put in an abstract to present also at the HACC conference next year and we have held some forums locally to get this information out. The University of New South Wales has conducted some research as well, so we have been presenting those findings out and about.

So we are very active. We have written to every politician and policymaker that we can think of and enclosed copies of the blueprint. We even made a T-shirt for Bill Shorten.

Senator BOYCE—Damn. Could you ask for it back!

Ms Haggett—And we have made a submission to the Productivity Commission.

Ms Hewitt—Yes, we have submitted to the Productivity Commission on the NDIS, the national care and support scheme.

Senator BOYCE—You blueprint refers to recognition as a special needs group within aged-care funding and the legislative framework, flexibility and collaboration among all levels of government and their departments and a number of other things. I think it would be fair to say these things do not currently happen.

Ms Hewitt—No, that is right.

Senator BOYCE—What is your planning around making that happen?

Ms Hewitt—As I said, we are certainly sending that information out to anybody we think might be able to influence those decisions and seeking audiences with those people. Beyond that, I am not sure whether you have any suggestions on how we might make that happen.

Senator BOYCE—This inquiry is intended to dovetail with the Productivity Commission’s work in looking at the intangibles, I guess. What makes planning a sustainable thing so that parents can feel comfortable—I am the parent of a 26-year-old with an intellectual disability—in saying, ‘I’m about to shuffle off this mortal coil, but it’ll all be fine’? Would you discuss that.

Ms Haggett—I would like to jump on my bandwagon. I am with a group and we have been working on setting up an intentional community for some time now. We did a feasibility study with ADHC, which we finished in March. We are now working on the finer details of that. It is a proposal to have people living independently much earlier. What we have to sell to the Treasury is that it is worth spending money earlier to have them integrated into the community in order to stop this crisis later. So our proposal is that you build a building and 15 per cent of people in this building are people with disabilities, the rest are whoever wants to live in the community.

Senator BOYCE—So they are units or something?

Ms Haggett—We are proposing a block of apartments, but it could be anything. It could be a row of terraces. But it is the proportion that is right. So you have people who are just neighbours or acquaintances who are there to give this informal support, but it does hinge on them getting enough formal support to manage. But it certainly is a lot less than a group home place would cost. My son has Down syndrome and diabetes, so he needs 24-hour monitoring but he does not need 24-hour care. This is much cheaper. We have been working on this and we are hoping to have it built in a year or two. We will get there, but it is horrendously hard to convince people. ADHC are working on the model with us.

Senator BOYCE—We were told this morning about a group trying to establish an intentional community who had been told by the state department that it was a lovely plan, but they would not guarantee that those parents' children would be the ones who would move into it, it would be anybody.

Ms Haggett—Well we are not in crisis, we are not deemed in crisis.

Senator BOYCE—So that is the case here too?

Ms Haggett—I think because we have been working with them, they may well fund this as a pilot, and that seems to be what is happening.

Ms Hewitt—But that is very true. Parents are usually lobbying on behalf of all parents rather than on behalf of themselves, and those people who are very active and vocal and coming up with ideas and banging on politicians' doors are often the ones who in the end are having to relinquish their son or daughter once they are in crisis themselves because despite all of these years of work they are not guaranteed that sort of support.

CHAIR—I want to go back to the other example. Are you looking at social housing and the community housing funding from the affordable housing package?

Ms Haggett—No, we are looking to sell the apartments. We are working with a community housing provider at the moment and what we would like to do is have some affordable housing, but have it financed by selling the rest. We have done a lot of market research and there is a market out there for people who want to live in communities.

CHAIR—Very definitely.

Ms Haggett—So that it could be self-funding, we would sell some in order to fund the others.

Ms Hewitt—This concept really could work in a number of ways. As Rachael said it does not necessarily need to be a unit block, but it is about establishing those communities. In a rural setting it might well be a collection of houses in a particular area that people agree that they are going to form this community, or it could be some villas or whatever in different communities. It is an ideal way, that intentionality about people making a commitment to support their neighbour. Not to care for them, but to support them.

CHAIR—Yes, I am aware of a couple in WA.

Ms Hewitt—Yes.

Ms Hayhoe—We are certainly very interested in working with community housing providers on those kinds of models and also developing accessible housing options for people with disabilities.

Ms Haggett—It is doing it early enough so you avoid the crisis.

Senator BOYCE—That is a question I have been asking the majority of people. Someone used 18 to 30 as the general age that people move out. I have been using 18 to 40—

Ms Hewitt—That’s right; it’s changing, isn’t it.

Senator BOYCE—But you do have an expectation that your children will leave home—

Ms Hewitt—And they do too.

Ms Haggett—But some of them come back.

CHAIR—Repeatedly!

Senator BOYCE—but the whole system around people with disability now seems to be somewhat predicated on the view that the children will stay home with their parents for as long as the parents can possibly cope.

Ms Hewitt—Until they drop.

Mr McNamara—Is the comfort in knowing there is a model or having an assurance that the resources are earmarked for support needs? From the aged-care perspective, looking at planning at a macro level, we have the planning benchmarks you are probably familiar with—for every 1,000 people aged over 70 it is so many places—and that is locked into the future. There is an expectation that there is going to be an increasing cost, and almost implicit in that benchmark is a provision for resources. Now that might not give every individual that is going to age and need aged-care an assurance that they will get it, but it does say that there is provision for it.

Senator BOYCE—We are considering that as an issue.

Mr McNamara—Whereas for this group there is no quantification, there is no provision. I am not saying it should be the same exactly.

Senator BOYCE—So how would you see that happening?

Mr McNamara—You would need to quantify it in the first instance—how many; where are they; how much will it cost—and start thinking about making some sort of provision for it. There is no doubt aged-care planning is locked in, unless somebody overturns it, and I do not see that happening pretty soon

Senator BOYCE—There are too many voters in the aged-care area.

Ms Hewitt—With a register such as you are suggesting, it certainly could be possible for that kind of tracking, and those figures could be extrapolated.

Ms Haggett—It is about trying to be more clever with the funding too. A lot of parents would be happy to buy an apartment for their son or daughter, and we have done that for our son—he is getting 24-hour support from live-in housemates, who live there rent free—but you get no tax incentives to do that. Even if you got land tax off or got some help with electricity bills or something like that, that would encourage a lot more people to do it, I think.

Senator BOYCE—Or put it into a special disability trust.

Ms Haggett—Yes, something like that.

CHAIR—Because the other issue there is the implication for you, in terms of how the second house counts, when you retire. We have come across that as well.

Ms Haggett—There is not much incentive to do it yourself. We have done it because we do not want to have a crisis in the future. So thinking about how to do that better would be good idea.

Senator BOYCE—One of the things we have talked about, on that question of ‘what happens when I’m no longer able to care’, is that the plan, whatever it is, should be flexible but sustainable. Could you describe what makes the intentional community sustainable.

Ms Haggett—I went to visit Deohaeko in Canada, which is an intentional community they set up 15 years ago.

Senator BOYCE—What is it called?

Ms Haggett—Deohaeko. I will give you a brochure. I had a meeting with a parent and one of the residents there and I asked her that question: ‘What will happen when you’re no longer here?’ She said, ‘I know because other residents here don’t have parents and it is working for them.’ What you do is create a mixture of informal and formal supports. You get formal support from a disability provider and then you get informal support from the residents, but you also form a circle of support with family members—brothers, sisters, cousins—and family friends. In our case, ex-housemates are in the circle of support. Between all of that, it is sustainable in the long term. So the parents take an active role on the circle, but they are not the only carer. They have bigger support. I have found for my other children, who are both living overseas at the moment, it is reassuring. The circle itself reassures them. They feel part of that, but the onus is not just completely on them.

Senator BOYCE—Is not just them.

Ms Haggett—Yes. It is creating a network, I guess, that holds it and will be sustainable after you are not there. A lot of people do not have that—it is just you and that is it, and that creates the expensive crisis. That is what we are concerned about.

Senator BOYCE—Would any of you like to comment on how you might go about establishing networks for people who are not able to build their own?

Ms Hewitt—My organisation is currently being funded by the Department of Ageing, Disability and Home Care to do what is labelled an independent living skills program but it is a bit more than that. It is a pilot. It is about working with people who are living at home with their ageing carer—so their carer needs to be over the age of 60—and providing up to 35 hours a week of drop-in support, whether that be at home or to help them to move out of home. That could be to a supportive environment, which might be like Rachael's son with flatmates, or it could be to the granny flat of the brother's house. It would be looking at what the options are for that person, assisting them to move out and providing them with care, and also helping the family build circles of support to make that care sustainable.

At the moment that is for five people on a waiting list that is massive. One can hope that it will be a model rolled out and available to more families than just this small cohort of five. Those are the kinds of practices that we really need to be moving towards. Hopefully, by providing those people with up to 35 hours per week of support, it is quite different and more cost effective than their eventual admission into a group home.

Senator BOYCE—So some of that support is planning?

Ms Hewitt—Yes, absolutely.

Senator CAROL BROWN—I was just wondering whether you could give us some more information about the one government agency and how you would see that working across the federal and state jurisdictions.

Mr McNamara—That all people with a disability who are ageing be supported under the one program managed by the one government agency? Is that what you are saying?

Senator CAROL BROWN—I am just—

Ms Hewitt—In saying that, I do not necessarily think that it means that one government agency provides everything but that perhaps there is a coordinating body that actually looks at the needs of people with a disability who are ageing and enables some of the various funding programs to work together so that you do not get a situation where it is either/or, where you are either attached to a state program or you are attached to a Commonwealth program or you are in HAC or something else.

CHAIR—In other words, you can access whatever you need from the suite of what is available.

Ms Hewitt—That is right—what you need and what suite of services you need in order to package support around you. We saw that perhaps having a coordinating body was the way to go with that.

Ms Hayhoe—I think it is also so that you have pathways for people to be able to have their needs responded to as their needs change and life circumstances change.

Ms Hewitt—And you are not having to look everywhere for it and piece it all together.

Senator CAROL BROWN—Do you see that that body would be situation at the federal level?

Ms Hewitt—That would probably be ideal, given that different states have different arrangements around their disability funding.

Senator CAROL BROWN—And obviously the idea would be that there would be input from other local governments?

Ms Hewitt—Sure.

CHAIR—As you can see, we are deeply interested in this issue. Your evidence has been very much appreciated and very helpful for us. I think there is a slight bit of homework.

Mr McNamara—Yes, the brochure.

CHAIR—Was there anything else?

Ms Hewitt—No. We would like to leave you these if that is all right.

CHAIR—That would be great.

Mr McNamara—And there is the review.

CHAIR—I knew there was something else.

Mr McNamara—The reason that the pilot was discontinued.

CHAIR—Yes, the evaluation.

Ms Hewitt—I think that is available from FaHCSIA.

Ms Hayhoe—Would you like a copy of the evaluation?

CHAIR—That would be appreciated, if you could. It might be easier for us to get it from you.

Ms Hayhoe—We can email that to you. We are happy to do that.

CHAIR—So far this morning we have been told of four pilots just in New South Wales. So I am keeping a tally.

Senator BOYCE—We are likely to get the pilots confused by the end of the morning.

CHAIR—We have had three witnesses already and we are up to four pilots that have all been discontinued. They all sound like they have been working well. One of the issues is this continual, ‘We’ll do a pilot here. We know it is successful but we will do something else.’

Senator BOYCE—Sounds a bit like the Indigenous area, doesn’t it?

Ms Haggett—It all sounds good but does not actually lead to anything.

CHAIR—Exactly. It makes people feel good for a while—that the funders were doing something—but then it does not go anywhere. We learn and then another one comes up.

Ms Hewitt—Absolutely.

CHAIR—Thank you very much for appearing today.

[11.34 pm]

CRAWFORD, Mrs Lucy, Executive Manager, Mai-Wel Ltd

HASKAL, Mrs Margaret, Executive Manager, Mai-Wel Ltd

CHAIR—Welcome. I understand that you have been given information on parliamentary privilege and the protection of witnesses and evidence. We have your submission, which we have numbered 43. I invite you to make an opening statement and then we will ask you some questions.

Mrs Crawford—Thank you. I thought we would start by giving you a brief introduction to Mai-Wel. Mai-Wel has been providing services to adults with a disability in the Hunter region for 50 years. We are based in Maitland and offer services in seven LGAs, including smaller towns in the Upper Hunter and rural towns—for example, Scone, Denman and Merriwa. Mai-Wel's experience in planning options and services for people with a disability who are ageing are similar to those in other regional areas. We do quite a lot of networking with other services in the area and attend national disability services, ageing subcommittees and accommodation subcommittees. So we are in quite regular contact with other service providers in our area sharing the same issues. The challenges experienced by people with a disability who are ageing are evident in our division, such as with our supported employees in ADEs, the residents of our supported accommodation service, group homes and our drop-in services as well as other older Mai-Wel clients who are living at home with ageing carers but may attend our day programs or our leisure link programs.

A significant number of Mai-Wel clients have been with the organisation since its inception. The organisation -Wel was started by parents of people with a disability who could see their children were reaching the age when they needed to leave school. They started a sheltered workshop—as it was referred to at the time—and then created some accommodation options and it has grown from there. Many of the carers are in their seventies and eighties or have deceased and therefore other family members are now taking on that caring role.

The service options that are currently available through our organisation include the individual service plan. We have futures planning within that component and provide education and support to carers to access a wide range of other services that help with the futures planning process. We are very active at client expos, providing service handbooks and the like around the futures planning.

Mai-Wel has seen some very positive outcomes through the Stronger Together funding and the creation of the life choices and active ageing programs. We have been lucky enough to have those programs within our organisation, and some people have been able to move into those. Unfortunately, there are still some barriers within the planning and access to those programs. I think only 10 people over our entire organisation were able to get places in those programs. It has been Mai-Wel's experience that accessing services for people with a disability who are ageing is inequitable. It is based on crisis rather than forward planning, and there are insufficient programs and services out there to meet the needs of all those who require them. The examples provided are what Mai-Wel clients have experienced to date.

For many carers of ageing people with a disability, there is a significant difference between what their goals are through the futures planning process. We get people with a disability and their carers to identify goals—what they would like to do in their retirement and what their plans are. Those goals and the opportunities that are realistically available for them vary quite significantly.

Mai-Wel has 106 supported employees. Of these, 33 are aged over 45, with six aged over 60 years of age and our oldest being 72. Currently there are 12 supported employees who are in immediate need of funding to access a day program.

Senator BOYCE—Retired from work?

Mrs Crawford—Yes. Their productivity rates are very low. They have mobility and health needs that cannot be supported within their ADE. What we have been able to do as an organisation is to have some flexible work arrangements in place, so they have been able to reduce their days or their hours of work, but that can only happen to a point because their carers then need to be able to provide support on the days when they are not working. Currently, they are being supported in an unsustainable, underfunded day program, one to two days a week and Mai-Wel has been able to create that program through fundraising but that only goes so far. It is the sustainability of that which is in question.

Many people in this group have had to remain in employment despite a desire or a need to retire. They have no funding to purchase a day program placement. HACC funded day programs have no vacancies, are non-existent or are just unsuitable to meet the specific needs of the client group. A number of the supported employees live in our group homes and those homes are only supportive from three o’clock in the afternoon until nine o’clock the following morning. We are not funded to provide support other than that.

The other issue is that while many of these people remain working even for a few hours a week they are actually ineligible for the Life Choices or Active Ageing funding and nobody wants to stop work in the hope that they may get a placement in the Active Ageing program. Our experience has been that the transition between state and federally funded services is blocked. If you are in an ADE, there is no real transition path into the other options such as retirement. You need to be able to secure a state funded day program before you are game enough to move out of the ADE.

The push for people with a disability who are ageing to be supported in volunteer community programs is of concern to us. Many of our clients have, as I said before, been with Mai-Wel and been within a disability support system for most of their lives. Venturing into mainstream aged care day care type of placements, which in our area are predominantly run by volunteers, has some uncertainty and, I guess, an element of risk. To assume that they will integrate into mainstream services without support, we believe, is not feasible for the majority of clients exiting our ADEs.

From the supported accommodation perspective, we have 32 residents living in Maitland. Of these more than half are 50 years of age. Most of these residents are still in employment regardless of whether that is their real want or desire. They keep being encouraged to go to work on a daily basis because we do not have the funds to support them to do anything else throughout the day. Most of our residents are block funded and that funding does not allow for any individual funding to purchase a day program. There is an inability to obtain Life Choices or Active Ageing funding as I said before. Despite the fact that we have put in two applications for this group of people, they have not yet been seen as a priority and there is no real transition process as I have said.

The majority of Mai-Wel's ageing clients are still living at home many with carers in their 70s and 80s and some do access block funded group based programs. That is funded by ADHC and then topped up which enables us to increase the need through the fundraising. The block funding or the Active Ageing and Life Choices programs only enable people to attend for up to 18 hours of support a week. If they have been employed for five days who picks up the rest of the support throughout the week?

With respect to some of the changes that would assist planning options and services for people with a disability who are ageing, we see a need for more long-term or lifelong case management. At the moment case managers are allocated pretty much based on crisis. If you get into a crisis you are encouraged to apply for a case manager. People can be waiting up to 12 months in our region to have a case manager allocated, and they are predominantly allocated through ADHC, so people have to go and retell their story, whereas there is the potential within some of our programs at Mai-Wel to actually do case management and be funded for case management. We do that for people we already know, who already have a strong connection with the organisation and have trust in the people that they are working with.

On effective data collection, I think we have already heard from other speakers that more effective data collection is really necessary because the regions do not really have any idea of how many people we are trying to plan for at any one time. There should be a greater equity of service hours. With some people, yes, the squeaky wheel gets more service, and there are plenty of people missing out.

Mrs Haskal—I would like to make a few comments about Mai-Wel's retirement planning. Obviously retirement planning is very important for an organisation that has over 100 supported employees. We acknowledge that for all employees, as for all other employees in the community, there needs to be some planning process in place. We also acknowledge that for people with a disability this may well be a staged process, beginning with the development of a retirement plan and then having a number of steps until retirement finally takes place and there is an exit from the workplace. There are things like sampling of retirement options. If you have been in an ADE or an Australian business enterprise for 40-odd years, you really do not know what options are out there, so there is sampling of those. There is also reducing their work hours so that they can access a generic or disability-specific day program. We believe that the federal government has some role in this. At the moment they do not give us funds to be able to assist supported employees down the retirement process, and I think that is something that they could do by way of releasing the older supported employees to be able to access some of those options.

Mai-Wel have done a number of other things too that other services are doing or could certainly duplicate. One of those is that we have trained some staff both in aged care and in disabilities. That is helped because we are a registered training organisation. It has certainly assisted us in providing a better quality service to our people with a disability who are ageing. We have also established a relationship with an aged-care facility in Scone. As a result of that relationship we share training and service ideas. That has worked well for a number of years. Since 2003 we have had that relationship. We have also developed relationships with dementia specific services, for example, to allow our staff to plan and assist clients who have early onset dementia. This has resulted in us developing an assessment for early onset dementia, particularly for our clients who have Down syndrome.

Finally, I think it is rather sad that we have 12 supported employees who are depending on fundraising for their retirement. I would like know what the Australian population at large would think if we decided that their retirement would be funded through fundraising. Also, I think it is very sad that one of the biggest concerns for older carers is: ‘What is going to happen to my son or daughter when I die?’ The reality in 2010 is that a lot of them die not knowing.

Senator BOYCE—I am playing the devil’s advocate here: why federal government funding to pay for retirement and not state funding? The states currently have the disability side of funding.

Mrs Haskal—We have outlined that there is a blockage between the passing over of federal and state funding. Once you leave an ADE, you need to be funded by a state. The reality is that many of the supported employees not only in our ADE but in ADEs across Australia have been in a federally funded system for years. Some of them have been in those ADEs for 40-odd years. The federal government know the clients. They have data on the clients. I am not suggesting for one minute that the federal government take over the provision of day programming, but as an initial step the federal government could release them from some of their hours as they are getting older to do some things like sampling employment options outside or to do a bit of retirement planning.

Senator BOYCE—You have obviously retired. Could you talk about how you did that? You talked a bit about it, but could you give us some more detail?

Mrs Haskal—Essentially, those people have been retired out of business services for days only; they have not retired permanently.

Senator BOYCE—They have retired for as much funding as they can raise for the day programs?

Mrs Haskal—That is right. The days have been reduced and the amount of service they are getting is dependent upon our ability to raise independent funds to be able to support them.

CHAIR—Outside employment?

Mrs Haskal—Yes.

Mrs Crawford—And they have retired into programs that are very structured and very group orientated, and for the majority of people it meant that they are going to a day program with the people whom they live with. I love my family to death but having to do everything with them 24 hours a day seven days a week is not necessarily what I would choose to do in my retirement.

CHAIR—Are they structured for what somebody might want to do in their retirement?

Mrs Haskal—Yes. The reality is that they do not have the option of retiring at home. In an ideal world, it would be wonderful if they could reduce their working day by one or two days a week and then go back to their residence, but we are not funded during the day. The whole of the accommodation service is based on the fact that people would go to work from nine until three. That makes it difficult. There is a huge demand for supported accommodation.

Senator BOYCE—You could talk a bit more about that and how you see people transitioning. In an ideal world what would happen? Do some of your people still live at home with their parents?

Mrs Haskal—Yes, the vast majority.

Senator BOYCE—I know that over the years parents have seen that having the person work in an ADE is a respite for them. Is it possible for those people to have something more like a normal retirement where they would spend more time at home, or do families need that time to stay fit enough to look after them the rest of the time?

Mrs Crawford—There are certainly some examples of some carers in their mid- to late 80s who have quite significant medical and mobility issues. Yes, the person could probably stay at home with that carer but not a lot would be done during the day. Then you have the problem of someone who has worked most of their life then having to spend a lot of time at home sedately and that impacts on their physical and mental wellbeing.

Senator BOYCE—I was not suggesting that they just stay at home all the time. I was wondering if there were any other impediments to having some time where they just watch *Days of our Lives* or whatever.

Mrs Haskal—They could well do that. A good example is a lady who worked in business services for years. She recently retired and was going to stay home with mum or dad, but unfortunately shortly after she retired mum went into hospital and is very ill. The parents are in their 80s. They thought that when she retired she would stay at home and her unmarried aunt would come and they would do things together. It just shows that the circumstances can change. You are dealing with a vulnerable group of people. What can happen to some people with a disability is that they become pseudo-carers for their ageing parents.

Senator BOYCE—There is a lot of co-dependence.

Mrs Haskal—Yet there is a lot of co-dependence but sometimes there is no choice.

Mrs Crawford—A number of people in the ADEs are not known to ADHC because they have only been funded by the federal system. Although it may be recognised that this lady is in a crisis situation now that her mum has gone into hospital that eligibility process of getting a case manager and being able to access other services takes quite a time. We have had the experience where people have been in an ADE for many, many years but when they transfer over to ADHC funded services, we have to prove their eligibility for those services.

Senator BOYCE—To prove they exist.

Mrs Haskal—Exactly, and that they have a disability.

Mrs Crawford—It is quite bizarre.

CHAIR—This goes to the issue of data and unmet need. That group of people are not being counted at the state level—they may be at the federal level.

Mrs Crawford—That is right. They are not registered.

CHAIR—Is that just specific to New South Wales or do some of the other states register people who are in an ADE?

Mrs Crawford—I am not aware of what the other states do.

Mrs Haskal—I don’t think there is anywhere.

CHAIR—Unless they have come up as requests for support when they were younger.

Mrs Haskal—There certainly are advantages getting a case manager from the New South Wales Department of Ageing, Disability and Home Care because you have an advocate. But getting a case worker is very difficult. I am sure that the demand far outweighs the supply but you could wait months to get a case manager, through that department, to assist. That is not because they are lazy; it is simply because the demand is much greater than the supply.

Senator BOYCE—I was really interested to hear you talk about having developed an aged-care disability training package. Could you tell us a bit about that, because that has been mentioned quite a lot in evidence.

Mrs Haskal—We are a registered trainee organisation and we develop both community services and aged-care qualifications. We have some staff who are currently going through, I think, cert IV in aged care and we have the equivalent in disability services too. But it can also mean just doing modules. The idea that you have to get a total qualification is just not right. You can select the modules in aged care that are appropriate to your service and deliver them through an RTO. You can deliver them using existing worker traineeships. Mai-Wel has been able to provide a well-trained staff because we have used existing worker traineeships.

Senator BOYCE—Just give us a quick snapshot of the sorts of modules that your staff might be doing and what that means they can do that they could not do before.

Mrs Haskal—Well, they might do a specific thing on working with clients who are ageing. I think that is one of the modules. It would go into the different care requirements as you get older, in terms of mobility and medication, and it would look at the legal responsibilities. One of the units is on legal and ethical issues. There are lots of legal and ethical issues around ageing. There is a different charter and the organisation that gave evidence before was talking about the different standards. Yes, there are different standards and I think you need to understand those. There is a different focus, too, between aged care and disability.

Senator BOYCE—You were talking about an assessment for early onset dementia. Have you developed an assessment tool? Could you tell us how you went about doing that?

Mrs Crawford—A lot of the areas are taken out of the Service Need Assessment Profile service—SNAP—assessment, so what I have done is just draw particular areas out of that. Through the staff observations of the clients, they are just recording against those particular areas any changes in support needs and additional supports that they have had to do. So it is more of an observation based assessment than anything else, and there is certainly a lot of room for improvement. I have recently started up a local forum, trying to draw together a number of service providers who are dealing with the same challenges that we are around supporting people to age in place, and one of the things that we are looking at next year is to get the Alzheimer's association on board, hopefully, so that we can tease out that assessment and build on it. It is just a very basic assessment at the moment, but I have used it for three of our residents who have since transferred to aged care facilities and, not long after doing so, passed away. But, when they were attending the geriatrician's appointments, it really helped get a very quick diagnosis around dementia for those particular people, because you could see very clearly when things started to change. So the protocol that we have in our organisation now is that that commences with anybody with Down syndrome who is 40 so we can establish that baseline and a benchmark. Then we can map and see any changes from there.

CHAIR—Do you know if other organisations are taking a similar approach?

Mrs Crawford—With this forum that I have established, that is something that they certainly want to do. At the last meeting that we had, I got everybody to bring their assessment tools or observation charts and that sort of thing, and people are doing it through multiple forms. So they have something about mobility and then about something else and something else again. Trying to bring all that together is what we are really trying to do there.

Mrs Haskal—This also translates to different service provision too, because we have recently hired a creative arts facilitator, and part of the role of the creative arts facilitator is to make memory books. They are doing scrapbooking for clients who have Down syndrome and are at risk of early onset dementia. So it is accumulating a history in terms of photographs and statements which the supporting staff could then use to provide a better service as the people—the clients—get older.

Mrs Crawford—What we have found with the residents who did have to transition to an aged-care facility because there just was not the funding, no matter how much we asked and lobbied for our funding to be increased, is that we were just told, 'No, you can't meet their support needs; you have to get an ACAT assessment and they'll have to transition out of your service.' We did not have these life stories in place. We did not have the staffing or the funding resources to do a really good transition process, so they left us one day with a staff member who we allowed to stay for a few hours and pass on as much information as they could, but that was the end. Apart from volunteer visits and staff themselves wanting to maintain a connection, they were gone.

CHAIR—How old were these people? The reason I am asking that is that we heard this morning that people have had trouble accessing ACAT assessment because somebody was not 60.

Mrs Crawford—Yes, they were under 60, and the only way that we could get an ACAT assessment done for these people was that ADHC needed to put in writing that they could no longer—

CHAIR—You could not cope.

Mrs Crawford—Yes, we could no longer provide accommodation because their needs exceeded—

CHAIR—There was a crisis situation—okay.

Mrs Haskal—But my understanding is that there is no age restriction on ACAT assessments, is there?

Senator BOYCE—No, but we understand there are guidelines which are somewhat more forcefully enforced in some places than in others.

Mrs Crawford—Yes, and it is mainly driven by the young people in the guidelines. It is like the two sides of government playing against each other: this is what ADHC are saying, yet they are still trying to put younger people into aged care.

CHAIR—We have been looking at a number of witnesses who have been talking about alternative assessment tools for people who are ageing with a disability, because—you have just talked about it—there are different needs for assessment. I think it was this morning that there were suggestions that there are already tools used overseas that we could adapt and use.

Senator BOYCE—The Down Syndrome Association was suggesting that there were tools in existence in the US and the UK.

CHAIR—You have been doing your own as well.

Mrs Crawford—Yes. I have had a look at the one the Down Syndrome Association put together, but it needs to be very heavily resourced to be able to do it properly, because it relies on collecting visual evidence—videotaping a person doing particular tasks—and a lot of the generic dementia assessment is wound into it. They ask cognitive types of questions—who is the Prime Minister; in what year did such and such happen? A number of our clients with an intellectual disability could not answer those anyway, and I would probably struggle with some of them too.

CHAIR—I have a question around regional versus city resources. Is the situation you are in, in Maitland, basically the same as what happens in the city, or are there regional differences? What are the issues around city versus regional?

Mrs Haskal—Probably the biggest is the transport issue, the distance issue. That impacts on service delivery because it is a cost.

Mrs Crawford—Apart from the transport issue, I cannot see many significant differences. I have been part of the large residential centres redevelopment project and the 14 services involved in that, sitting around the table, have all shared exactly the same challenges, apart from transport.

Mrs Haskal—And maybe access to specialist services. That is an issue, particularly speech pathology and those kinds of services that are required.

Senator BOYCE—This goes back to the point that you made, Mrs Haskal, around parents wanting to be able to say, ‘Harry’s going to be safe, even when I’m not here.’ What are some things that you think could happen that would assist in that?

Mrs Haskal—It goes back to the data collection and government departments having some idea of how many people out there require a service. We got a gauge from the Life Choices and Active Ageing Program, when it was first introduced. I believe that ADHC was probably overwhelmed with the response. They had no comprehension that so many people would be applying for that funding. It is about having an awareness of how many people are out there and when services are likely to be required and making a service system that you can navigate. Believe me, to navigate the service system—

Senator BOYCE—You are not the first person who has told me that.

Mrs Haskal—The poor oldies—they put their hands up in the air and say, ‘Where do I go to from here?’ particularly if they get a number of knock-backs. At this moment, if an older couple wanted supported accommodation in Maitland, they would have to go to HRSAPP—

Senator BOYCE—What does that stand for?

Mrs Crawford—The Hunter Region Supported Accommodation Placement Panel.

Mrs Haskal—If you want supported accommodation, you make an application to that panel, but the demand far outweighs the supply. There are not a great number of vacancies. Even when our older people are trying to find options for their sons and daughters who are ageing, they meet blockages. Sometimes they seem to be insurmountable.

Mrs Crawford—Because of the close-knit community of Maitland and Mai-Wel, they all share their stories. One gentleman in particular needed to go into supported accommodation. His father helped establish Mai-Wel is an organisation. He could not get a placement in any of our supported accommodation. For the first time in his life he had to go to Newcastle. He is now living in Newcastle and his mum stays in Telarah. There is a fear factor: not trying to do anything or wanting to put the name forward for the panel until there is a real crisis. They are fearful of what the options are going to be.

Senator BOYCE—If you do not like the first option, you might as well go to the bottom of the queue and expect that you will never be offered anything again—is that correct?

Mrs Crawford—That is right. One of the models that a number of our carers are very interested in is intentional communities. We put a proposal to ADHC about two years ago.

Senator BOYCE—What was that to do, just roughly?

Mrs Crawford—That was to establish something very similar to what the Futures Alliance was talking about. Ours was mainly for people with a disability who would live with their carers and have staff support building their independent living skills in partnership with the carer involved and building that support network, as the Futures Alliance spoke about, to then make it a sustainable arrangement when the carer could no longer provide that care because they have passed away or had to move into an aged-care facility. That did not get off the ground.

Senator BOYCE—Why was that? Do you know why it did not get off the ground?

Mrs Crawford—After several meetings and trips backwards and forwards to Sydney it all went very silent. We have not got a firm answer as to why it was not followed through with. I believe one service in the Sydney area did get some funding to do an intentional community, but to this day I am not quite sure who that is. I have not been able to find that out.

The model that carers seem to be really interested in at the moment is the shared care model. We would establish a six- to eight-bedroom home and clients would come for three nights a week and then they would go back and spend the remainder of the week with their family.

CHAIR—Which is a transition process as well.

Mrs Crawford—Yes.

Senator BOYCE—Is this transition planning?

Mrs Crawford—This is part of transition planning. So we will be able to support up to 12 families a week under that model through a transition planning process. We have done it informally. We have a four-bedroom unfunded respite facility that was set up again through fundraising—it was set up through our women’s auxiliary—and we have been able to get some small blocks of funding here and there from ADEC for people to do exactly that as part of their transition process. That is going back a few years now, but they did that.

That was very successful. Three of those ladies are now living in one of our group homes. One of those ladies has had both of her parents pass away since, but it was really important for the parents to be part of that whole process and to see it through to the very end. Their transition to the group home was far smoother than for the people who have just come immediately to us and have had to move straight into a group home.

Senator BOYCE—And that has been because it is crisis driven?

Mrs Crawford—Because it is crisis driven, yes.

Mrs Haskal—I think the good thing about that model is that it maintains the carer’s role. Being a carer is a very important role and they would like to maintain that. Having a break in the shared care role allows them to re-energise for the days when their sons and daughters are at home. They do take their caring role very seriously.

CHAIR—Thank you very much. We very much appreciate it.

Proceedings suspended from 12.13 pm to 1.15 pm

BARNES, Ms Sue, Manager, Individual Advocacy, People with Disability Australia

BLEASDALE, Mr Michael Peter, Executive Director, Leadership Team, People with Disability Australia

CHAIR—Welcome. Before we start, I understand that you have been given information on parliamentary privilege and the protection of witnesses and evidence; is that correct?

Ms Barnes—Yes.

CHAIR—We have your submission. It is numbered 52. I would like to invite either of you or both of you to make an opening statement, and then we will ask you some questions.

Ms Barnes—Thank you very much for the opportunity to appear before this committee. People with Disability Australia, or PWD, as I will continue to refer to our organisation, are a national disability rights and advocacy organisation. We operate from an international human rights framework and provide a number of activities, which include individual, group and systemic advocacy; consumer protection; information; education; and training. PWD were founded in 1980 to provide people with disability with a voice of our own. PWD thus represents the views and interests of its members, the majority of whom are people with disability or organisations governed by a majority of people with disability. We also have a cross-disability focus, in that membership is open to people with all types of disability. We also work with numerous people with disability who live in extremely marginalised and vulnerable situations, including those people who live in licensed boarding houses or in institutional environments or who come under the Public Guardian or the New South Wales Trustee and Guardian.

As previously stated, we work within a human rights framework, and PWD have extensive human rights expertise, particularly in relation to people with disability. We recognise people with disability as rights bearers and interpret their needs and concerns in terms of human rights. PWD advocated for many years for the development of an international law that would provide a consistent framework for the protection and promotion of the rights of people with disability. This law, the UN Convention on the Rights of Persons with Disabilities, or CRPD, as I will continue to refer to it, was developed over several years, and PWD is proud to say that it played a significant role in representing the views of people with disability in Australia, conducting two national consultations on behalf of the Australian government of the day, participating in several of the UN ad hoc committee meetings in New York and representing the views of people with disability in Australia to that committee. The Australian government ratified the CRPD in July 2008, making a commitment to realise the rights of people with disability in Australia, and this commitment extends to state and territory governments.

Now that Australia has ratified the CRPD, and in keeping with this commitment, we propose that this inquiry should use the CRPD as an essential interpretive aid to audit and assess all recommendations put forward to the inquiry regarding the access to options for and services to assist people with disability and their carers to plan for the future and to ensure that legislative frameworks, institutional arrangements and practices that underpin these services conform to the CRPD.

PWD is very aware of longstanding issues and concerns for people with disability in ensuring (1) that they receive services and support which enhance their quality of life, (2) that they have choice available and (3) funding of planning options to people ageing with a disability and their carers. We have raised many of these issues in our submission, and our comments reflect the lived experience of people with disability. We have illustrated through individual case stories and presented the effects that the long-term failure of governments to plan for the future in the disability sector has on people with disability, which have resulted in major human rights abuses for those individuals.

We would also like to emphasise that access to options for and services to assist people with disability should not be limited to the one time a person with disability leaves their family home but rather should be provided on an ongoing basis as their needs, circumstances and lives evolve. Some key principles which we wish to highlight when considering access to options for and services to assist include enhancement of self-determination, preferably through mechanisms which promote individualised funding and self-directed supports; flexibility and recognition of the culture, values and preferences of each person and, where appropriate, their family; disability policy and practice which is broader than disability service provision; and policy and practice that recognise that it is society which creates significant barriers for people with disability and that it is the barriers which need to be fixed, not people with disability. A shift is required to put the person back in the centre of policy and practice, with the recognition that people with disability want to work, live in and engage with their communities on an equal basis with others.

As stated in our submission, PWD fully supports the introduction of the National Disability Insurance Scheme, the NDIS, as currently being considered by the Australian government. We recommend that the NDIS provides a mechanism for individualised funding options, as it is a way for people with disability to have control over planning and services, ensures that their individual needs are met and affords a continued quality of life regardless of age and changing circumstances. PWD believes the NDIS should model the CRPD throughout its implementation and therefore be open to all people with disability as an entitlement.

We also wish to emphasise to the committee our concerns about the systemic structures and policies which create unnecessary barriers and exclusions to disability services and supports on the basis of age. Choice and funding of planning options for people with disability must ensure that those who have attained the age of 65 are not provided with inferior options purely because they are forced to access services through the aged-care sector rather than the disability services sector. A large range of service delivery options must be available to accommodate the difference and diversity of people’s needs and to reflect their different aspirations, even in their old age. Any tendency to a one-size-fits-all-models service must be avoided at all cost.

One final point relates to the dire need for access to adequate funded advocacy support for people with disability and their carers. Advocacy support is often essential for these parties to be able to negotiate the disability service system to ensure the provision of services which meet their needs and ensure continued quality of life. We recommend that governments agree to improve the funding and administration of advocacy support, with a focus on improving service delivery and access to advocacy for people with disability, the aim of this being that people with disability have access to independent disability advocacy that promotes, protects and ensures their full and equal enjoyment of human rights and enables them to participate as valued members of the community and to pursue their life goals. We thank you for the opportunity to make this statement and would be pleased to discuss any questions the committee wishes to raise.

CHAIR—Thank you.

Senator BOYCE—Could I first ask for a clarification. You mentioned that PWD has a fundamental commitment to self-help and self-representation for people with disability by people with disability. Could you explain how you do that with people with an intellectual disability or a cognitive impairment of some sort?

Ms Barnes—In terms of any advocacy support that a person may require, we have an intake process for access to services, as many other services do. We try our very best to engage with that person around their own views and how those might inform the situation they are currently in or the future. We work also with their carer or guardian to ensure that the best options come for that person. So there are a variety of mechanisms of communication with people to try and identify those things. But I suppose that, where a person is unable to engage in a significant way in that process, then we have to look at what would be the best-practice options for that person. Some of that is informed, obviously, by contemporary practice but also, in our organisation, by a philosophical standpoint around how we view the future for people with disability in this community.

Mr Bleasdale—Sue is correct. We do a lot of operational work which involves working directly with people with intellectual disability and also people with psychosocial disability and acquired brain injury. We also have the National Disability Abuse and Neglect Hotline and the Complaints Resolution and Referral Service, and I would suppose the bulk of clients would fall into those categories. But, as a membership organisation, we always have had and still retain members who identify as being people with intellectual disability and, in the other range, people with cognitive disability. Recently, at our AGM we voted in some constitutional changes which will assist people with cognitive impairment to access membership of the board. We were aware that those complex board structures sometimes are an impediment to people getting access to the board, so we are beginning to address those things as well.

Senator BOYCE—Sometimes when we talk about hearing the voices of people with disability we are really talking about hearing from articulate people with primarily a physical disability, not the broad disability community, for want of a better description.

Mr Bleasdale—Certainly. We are one of few organisations in the country that identify across disability and across the country, and I think that strengthens our position. Admittedly, a lot of the voices on the board are those of people with sensory impairment, physical disability or psychosocial disability. As I said, we are moving to get broader representation within the bounds of our constitution to achieve that representation, but we do feel in our day-to-day work that we are in tune with a lot of those issues that are happening on the ground through our operations.

Senator BOYCE—It is the subject of another inquiry, but I have always been fascinated as to how you meet the laws of corporate governance and at the same time have someone with impaired decision-making skills on your board. It is quite tricky—and congratulations if you have sorted it out.

Mr Bleasdale—I cannot say we have, but in a previous role I served on the New South Wales Council for Intellectual Disability and they have certainly addressed those issues extremely well and very successfully.

Senator BOYCE—You make the point that social support and social adjustment should be a right, not the result of pity or charity et cetera. Yet we have received almost unanimous evidence from the ACT, Victoria and New South Wales that all the services are currently crisis driven and that, if you make the most noise, you will possibly get some sort of service but there is no sense of anyone having a right to support. There is such a huge gap between the reality and these so-called ideals. How do we address that?

Ms Barnes—Could I be bold enough to suggest that a lot of that is determined by the amount of money put into the sector by government, whichever government. The crisis is largely an effect of failures to fund sufficiently in the past—so we have a historical backlog. You are quite right: it is crisis driven. Every person who ever calls our organisation who seeks support is usually coming from a position of crisis. We advocate really well for those people in that crisis and probably are able to achieve aims over and above somebody else who is now sitting in a queue. There are ways in which you can make government departments respond to that crisis situation, but it is not ideal by any means. I think it fundamentally comes down to how much money there is ever going to be available for in-home support, for other levels of support in the community, for accommodation and for other types of services that people might need.

At the moment, if you want accommodation in New South Wales you join a queue. You do not get to the top of that queue unless, really, you are in crisis and the only way to leapfrog the queue is if you are in crisis. That is a sad aspect of our work: families or individuals are often brought to the point where they resort to abandonment or to rendering a person theoretically homeless before there is a response. So certainly there needs to be a significant amount of investment across the range of services in the sector.

Mr Bleasdale—I would just like to add to that. Underpinning all of the four case studies that we have put in our submission there is a resource element, but they all illustrate real people who have ended up somewhere in the system where they have ultimately been forgotten and there is absolutely no way that the system, in the way it works at the moment, can pick them up as an individual and enable them to enjoy the kinds of rights and experiences that they are entitled to under the various pieces of legislation and, as we said, under CRPD.

I think there are real complexities in the Australian disability service sector and the community sector more broadly because of the state and federal distinction. I personally am not a fan of it and that is one of the reasons why we have been so supportive of a national disability insurance scheme, which we hope is going to have a single point of administration but multiple points of implementation on the ground, much more locally, and in a sense can override some of those state barriers. I do not want to necessarily point the finger at the states universally, but I think when we provide the states with the responsibility for the bulk of service provision through accommodation and other kinds of support services and they have to consider and weigh up their own state budgets and particular factors that are happening within the state at that particular time it becomes incredibly problematic. We cannot really talk about, universally, the rights of people with disability as citizens of Australia when it actually depends on where they are living, which state they are living in, which city, which country town, or whether they are out in the bush, remote, or in a metropolitan area. Those kinds of things all have to be weighed up. So it is very complex.

We have had a number of governments working very hard over a number of years to set up responses to people with disability, but there is no cohesion to those responses. There is no sense that I would imagine, beginning life as a person with disability, that I could see my way forward all the way through to old age, knowing how things are going to be laid out for me, how I am going to have opportunities for education and employment, where I am going to live when I choose where I want to live, those kinds of things. I think there needs to be a much greater focus upon how the various support and service industries we have set up can focus on the individual and assist that individual to develop as a human being and get what he or she needs throughout their life.

Senator BOYCE—We have taken evidence from several groups on the idea of identifying people with disabilities as a special needs group in the way that we identify Aboriginal and Torres Strait Islanders for early ageing—the fact that the aged-care system kicks in at 50. What is your view on that?

Mr Bleasdale—It is probably an ambiguous view. One of those problems that I described before, which is a state and federal thing but also a cross-sectorial thing, is the crossover between being a younger person with disability and suddenly getting into the aged-care sector. There are a whole range of things there where we believe that what is available within the aged-care sector is not adequate and probably not appropriate in many respects. We have been having this conversation for 20 years and we do not seem to have moved much further forward. There does not seem to be the political will—I do not know if you would call it that—on behalf of the Commonwealth and states to really nut that out. There have been a few initiatives, and they are laudable.

Senator BOYCE—But what about the situation of applying the current available ageing in place type funding to people who may currently live in supported accommodation, for example, and are demonstrating early onset dementia or something?

Mr Bleasdale—Maybe you know more, but I understand that it is not of the same sort of magnitude. It is not enough to be able to provide that. You face the possibility of having got a fully funded attendant care package of 35 hours a week and then, as soon as you hit 65, something different kicks in which is when, potentially, you might need more support than that. I think that is a fundamental barrier.

Ms Barnes—I think in general we would support the principle of ageing in place and that would be a preference for any person with a disability. Perhaps, if an age-related problem is arising, additional support can be put into support that person in their home, whether that is a group or an individual home. It would only get to a point if they really could not be supported there or their impact on the other people who were residing there needed to be addressed. That would be our preference and I am sure the preference of all the people who we work with to have that in place and the resources there to support that.

People have a right to stay in their home where the supports are wherever they come from and not be diverted into a sector too early that may not be responsive to their needs. Particularly if we are looking at a person with a cognitive impairment or an intellectual disability, the general aged care sector probably does not deal with those individuals terribly well. We have had examples of people who, because of age and other related behaviours that may have pointed to dementia or other early onset disease, have gone into the aged-care sector and they have found them very problematic and have exited them very quickly. I have a particular client who is currently residing in the Bloomfield psychiatric hospital at Orange because of that very factor. He was deposited on the doorstep because the aged-care sector could not deal with him in any way. He did not fit the norm of their normal residents. These are the kinds of other challenges that might fit into an existing sector that we have which may not be the best option for some people or it may not be their choice. The more people who can be supported outside of that sector would be something that we would specifically request.

Senator BOYCE—You undertake individual advocacy which I am assuming is probably, most of the time, based on a crisis or a longstanding problem.

Ms Barnes—Unfortunately, yes.

Senator BOYCE—Do you have people making a call for assistance with long-term planning for their adult child for instance?

Ms Barnes—We do. That is not the bulk of our work. Certainly, we have had calls for that kind of support or people just inquiring about where they can go. They are aware that they are ageing and that they are not going to be able to look after their son or daughter for much longer. They do not know what will happen. Twenty years ago they put their name down on a list with the department of ageing and disability and they have found out that that actually does not mean anything at all. There was some anticipation perhaps that at some point they might get to an age and there would be an accommodation for them, but unfortunately not. We can refer somebody in that situation to the government departments, who might be able to assist them with some planning around that through case management or other kinds of programs that they may or may not yet be setting up, or we can sit and have that discussion with them about the options to clarify what people may be looking for and move it from there. Unfortunately, that is probably fairly rare at this moment in time. There does not seem to be any mechanism where you can actually say to people, ‘These are the people who will help you with future planning and come up with resources for you.’

Senator BOYCE—Who in your view should be doing that? We have had evidence from a few service providers making the point that they appear to take an ISP to the level where it is a futures plan. I must admit I do have concerns about service providers, accommodation providers and whatever perhaps having a perceived conflict of interest in doing long-term planning. Who in your view should be the people doing the planning?

Mr Bleasdale—This sort of refers to our submission around the National Disability Insurance Scheme and the system that will flow from that, and we actually think that there is a third sector that needs to be funded to be able to provide that kind of independent advice and planning support to people. The short answer is that I do not think it exists at the moment. I do not think it is appropriate for us to be doing in it in our capacity as advocates. I think there will always be a case for advocacy to be there as a safeguard and for us to point out and identify people who are, for whatever reason, missing out or experiencing things like abuse and neglect. I think even that is separate from what we are talking about, which is real expertise in being able to get to know a person and do some planning right from the word go.

In terms of this inquiry—because I know we are really looking at the ageing issue—for us planning is something that happens over the life cycle. It has to happen early on and it has to happen at all those significant milestones. We are looking holistically at a person, so services may be part of the option for the person, but it is not all that it is about. That is one of the reasons I think that services cannot do it. They are restricted with ISPs. It is very much within the limitations of what they provide as a service, and quite rightly. How can they perceive what is going to go on outside? I think governments have been reluctant in the past to encourage it, because they probably—again quite rightly—know that there is not the sort of funding and the commitment to enable a person to really plan their life from beginning to end. Hopefully that is what we are beginning to see now—a growing and real commitment to the terms of the CRPD. I think with that commitment will come a commitment to then fund real, independent person-centred planning external to all of government services and advocacy.

Senator BOYCE—So you would see it as government-funded not for profits who specialise in doing planning. Would that be right?

Mr Bleasdale—Yes, that is a possible way. It operates like that almost on a commercial basis also in the United States and Canada where they get to do those things. It will be interesting to see, if the sector does get that kind of funding, what type of organisations will come. I would imagine there will be organisations initially.

Senator BOYCE—There are all sorts of organisations, including parent-run ones, that are trying to think around some part of the long-term planning. One last question from me: we have had quite a lot of evidence around the fact that it has become the norm for parents and carers to be expected that the person with the disability would live at home until the parent or the carer could no longer care. It has become almost an implicit given within the way the planning around this whole area happens. And yet for all other children you would expect that sometime between 18 and 40—and we have all made different jokes about this—they are going to leave home. From a rights perspective, do you think, firstly, that families should be able to have the same expectations about people leaving home in that normal span, so to speak; and, secondly, what do we do from a rights perspective to try to make that a reality?

Ms Barnes—Perhaps I could use as an example that the younger parents we deal with whose children are now in the 16 or so age group have an expectation that their children will leave home, the same as anybody else’s child will leave home—the same as my children have left home. We have got a historical factor that has led to this implicit idea for a group of people that ‘we care until we die’ almost. People may make choices about that, and that is for them.

Senator BOYCE—You care ‘about’ them until you die but necessarily care ‘for’ them.

Ms Barnes—That is right. We deal with those problems almost on a weekly basis when people contact us. That generation now, who will be looking at living their lives the way that everybody else is living their lives—leaving home, becoming independent from their parents, their families, and having those ongoing supports—the accommodation options and the support options are the key issues for them. For some that might mean moving easily, if one was available, into a group or shared house setting. For others, we are aware of people who have set up arrangements around their children where they have perhaps purchased the house themselves, so they have been fortunate enough to be able to afford that, and they have tried to get others to live with them—friends, other carers—and there might be a range of different personal arrangements around supporting somebody to live independently or as independently as possible within the community, much the same as most of our sons and daughters will go off into their young adult lives.

The major problem is getting access to the supports and access to the accommodation. Given that a lot of people will still be living on a disability support pension, which does not give a huge amount of funding, that could be fairly problematic for them establishing themselves. It is problematic. What we are observing is there is a wish from the younger generation for that lifestyle, for their son or daughter with a disability to live pretty much, as much as they can, the same as everybody else’s, and that they do not continue to care for the rest of their lives in that physical way that they may be doing living in the same house et cetera. But making that happen is not the easy option at the moment. Some have been successful, some middling, some have failed dismally, I suppose, and for others it is just a wish at this moment. It is something they would like to see realised, but how do we make it happen?

Mr Bleasdale—Historically, people with disability were always expected to be cared for at home, and it was only those people for whom home care was not available that we developed first of all the institutions and then we moved on from there. So I do not think we really factored in enough about what was the level of support that was needed when we closed institutions. An important thing to point out also is we have developed the other institutions in our society and our built environment around not accommodating people in independent accommodation in the community, and that is where there is a significant deficit. We need to extend our focus beyond services and support and funding. That is really important, but there is also: where do people live, what is the type of housing, how do people get around and about the community, what are the mechanisms within our regular society that are going to enable people with a range of disabilities to be able to function as independently as possible and to be able to facilitate that move out of the family home? I look around Australia and I see the environment is still built up around the family home and therefore and that is where people will live, and it is very difficult for people to move out of that environment.

Senator CAROL BROWN—You indicate your support for individual funding, and we have heard other submitters also support that. Are there currently individual funding arrangements in New South Wales?

Ms Barnes—There are numbers of small packages and that is more about directing the kind of services and supports that somebody might need in their daily life. But we are not talking about sufficient funding that would allow you to establish a house or any of those kinds of things. So it is more about service access, which somebody directs—

Senator CAROL BROWN—Self-direct the funding.

Ms Barnes—yes—rather than accepting day program funding and that is the only option. People would like to tailor other things around themselves. That has been coming on board, but it is still fairly limited in New South Wales. I do not know about the other states.

Senator CAROL BROWN—How much of the self-directed funding is happening here?

Mr Bleasdale—I am afraid I do not have all the details. The person after me will have those details for you. Sue is correct. It is not as we would like—that all funding that a person is provided for the purpose of supports and services is not able to be individualised at this moment. We understand that there are perhaps moves ahead—they have not been announced yet. That might be the case. That enables a person to make some more significant choices about the way in which that money is spent to be able to support them in the way they need. We have lots of little different types of programs and services and some of those are able to be individualised. Where that happens it does give a degree of choice and self-determination for a person, but you can only individualise and, if you like, direct a small amount of respite funding and yet the other types of supports are still block funded and you are still locked into that routine. It is not ideal. I guess we are looking for a broader—

Senator CAROL BROWN—Do you know how that is being rolled out? Are only particular people able to apply?

Mr Bleasdale—It tends to be rolled out in pilot projects. It is not widely available. I am not sure it would be available, even when it was in pilot form, to everybody in all parts of the state. As I said earlier, that will differ from the experience people have in other states. It might be better in some states or it might not be as good.

Senator CAROL BROWN—So, even in that muddled way, what is the feedback about how that self-direct funding is working?

Ms Barnes—Positively.

Mr Bleasdale—Yes. A good example in New South Wales would be the attendant care package. There are two options: in one you can be self-directed and in another you go through a chosen service provider. When people have gone through the self-directed way, universally there is an acceptance that they have much more control, they are much more satisfied and they are much more in charge. Ultimately, if you are in charge of your supports you are not necessarily conscious of that; you are just conscious of the fact that you are in charge of your life and the support is there to enable you to be in charge of your life. That is the key difference, rather than saying, ‘It’s six o’clock and they’re going to come around now because they have to service somebody else after me,’ they say, ‘What time am I going to require my personal care?’ and those sorts of things. It allows people to make decisions and lead their lives in the way they want. That is a very strong example in New South Wales which I would be very supportive of and where there is a very strong distinction between those who have it self-directed and those who still have it provided by providers.

Ms Barnes—For those who are not self-directing, one of the key problems that often arrives on our door—let’s take home care as an example—is that someone feels that the service is not adequate to their needs, in terms of the hours that they are able to access; that the service may not be provided at times in the day, or within the week, that suits them. There are those kinds of problems. They may have problems with a particular individual who is providing a service, which sometimes happens, unfortunately, and it is very difficult for them to be able to say, ‘Look, I am sorry—can you send somebody else tomorrow? I would much rather that.’

Allocation of hours, staff and things is very much at the behest of the home care service. A lot of complaints mechanisms fall into place then to try and address those things. For some people—and I am not suggesting for all people—it does lead to problems: you need to leave at a certain time to be able to get to your job and yet home care cannot come until after you are supposed to be a work. That is a very brief example. There are those kinds of things. Those who have much more control about that can say, ‘I’m sorry, but I’m purchasing a service. I would like you to be here at seven o’clock and, if you aren’t, perhaps we can renegotiate our contract around that,’ in the same way we have controls over many of those things in our lives and have choices about it.

Senator BOYCE—Unless it is a tradesman!

CHAIR—You wait all day.

Ms Barnes—Which most people do not want to do. It causes an awful lot of angst.

Senator CAROL BROWN—The other thing I wanted to touch on—and Senator Boyce talked about this earlier—is that in your opening statement you mentioned the inferior options for people with disabilities once they turn 65. We heard some evidence today about a pilot program that was set up as an interface between disability providers and the aged-care sector, where clients were able to access packages from each of the sectors. Have you heard about that?

Ms Barnes—I am not aware of that, no. Sorry.

CHAIR—I think there were only 10 that participated in that, weren’t there?

Senator CAROL BROWN—I think there were 30 over three years.

CHAIR—Okay, yes.

Senator BOYCE—That was pilot program No. 5, wasn’t it?

CHAIR—We have been commenting on the number of pilot programs that have been operating in this state.

Senator CAROL BROWN—Did you want to elaborate on the—I think these were your words— ‘inferior options’?

Mr Bleasdale—It has been a longstanding issue. I think we have taken far too long to get to it. To be perfectly honest with you, I do not think we have any firm recommendations about how it can be fixed. It sounds to me as if that pilot, albeit hopelessly restrictive, is probably the way to go. I think the good elements of both sectors need to be brought to bear.

I used to work in the non-government service sector. The predominant business was aged care and I worked within disability. So I had a chance to look at the two sectors in a particular project, but that was back in 1996. We did not really make much progress there and I do not think we have made much progress since. Aged care, for a start, is something that relies upon the funds of people who use it. A lot of the people that we know about are people who are affected by poverty or very low income. I think the aged care sector has difficulty in incorporating too many people who are in financial hardship. I am not sure they have developed models of ageing in place that are going to be able to sustain our people, not just because they have impairments that might challenge the skill sets of the people who work with them but also because of this issues of how we provide accommodation and the cost of all that. There are some really fundamental problems.

Our comment about inferiority was partly because we were aware of the types of packages that would be available to people to enable them to stay at home. Some of the restrictions around that might be similar to what I was talking about in terms of attendant care, where you have to be available. I think there is also an issue of expectation. If you have been a person who has lived with disability throughout your younger life, and you have had the good fortune to benefit from good support services, when you suddenly hit the aged care sector you find that there is a fundamental shift in expectation.

I could get myself into all sorts of trouble here because I have not worked close to it for a number of years but I was certainly aware of that a number of years ago. It really is an end-of-life type of sector: we have had a good life and we accept that there is a time in our lives when we are wearing out, we just want a bit of care and we want to forget about that. A younger person with a disability, who is approaching that time of life, still wants those fundamentals of autonomy and independence. They are absolutely fundamental to their way of life; it is really important to have control over those aspects of life. I am not sure the aged care sector, as it is currently constructed, will provide them with that. So there are a number of challenges there.

Senator BOYCE—I have one last question. It was mentioned earlier by people from the aged care sector that all the planning around the aged care sector is based on known statistics. There is nothing like that sort of planning in the disability sector, partly because we do not have the statistics. Would developing that sort of framework—where you know that in X number of years there is going to be X number of people in category A or B—be a useful thing to do in this area?

Ms Barnes—I certainly think that having some information would be really good. I think so, because if we are talking about individual planning for people there needs to be an intersection between that and the sector. It is fine having the best plans but you might want to realise that if, over here, they did not know about you, and you have no way of bringing the two together, that is not going to happen.

Currently, the government department in New South Wales, ADHC, have very few statistics on disability through the age and what might be anticipated and what people might wish for. I do not know how they would ever get the two together until they actually have some fundamental knowledge of the sector regarding what the demands are likely to be and when they are likely to be. I do not know that it is that difficult to project forward if you actually do the research, but that does not seem to be happening. I do not know what that is. Perhaps it has not been something that has been on anyone’s agenda. Perhaps, seeing as we seem to be crisis driven, there is no time to be looking at anything else.

Mr Bleasdale—I would be hesitant about getting much more by the way of data. It is inevitable that we need data around services and service needs, but my main concern is that there does not seem to be much data that indicates how well or otherwise people with a disability are faring in society. I think that is where we are really missing the statistical picture. That, unfortunately, is not going to help in relation to this particular problem. I am not sure what would. I get concerned around framing the issue of disability just as a service based issue. That would be my concern about having data that only looks at that and not having the data that also looks at how we are performing against the UNCRPD. That would be my only hesitation around that.

CHAIR—Thank you very much for appearing before us today.

Ms Barnes—Thank you for inviting us.

[2.04pm]

EPSTEIN-FRISCH, Ms Belinda Ruth, Systemic Advocate, Family Advocacy

CHAIR—Welcome. I understand that you have been given information on parliamentary privilege and the protection of witnesses and evidence. We have your submission. It is submission No. 2. I invite you to make an opening statement and then we will ask you some questions.

Ms Epstein-Frisch—Thank you. I will tell you a little bit about Family Advocacy. It is a New South Wales disability advocacy agency that works to enhance the voice of families in speaking out on behalf of people with disability. It recognises that families tend to be there in the long run for people with disability and if we can help their families to be more effective advocates on behalf of that person with a disability, the person with the disability will have a better life. As an advocacy agency, it is the centrality of the person with the disability. We are not a family support agency, but it recognises that, if families are effective in looking at the best interest and building a good life for their person with a disability, that person's life is better.

Our submission has argued that the majority of families have no access to support to plan for the future of their loved one who has a disability and that, in fact, the disability support system has created dependence in families and thwarted family initiative and planning. Recently the New South Wales government has embraced the language of 'person-centred planning' without any indication of understanding the structural change that is actually required in order to implement plans that are genuinely about the wishes and the needs of the person. Once again, the language changes but the lives of people with disability and their families remain the same. We have suggested to you that an organisation called Planned Individual Networks, PIN, in WA would be a good organisation for you to talk to. We could learn from them about real-life planning for a people with a disability.

Family Advocacy believes that the best way to secure the future for a person with a disability is to assist families to establish a home of their own for the person with a disability while the family still has the energy and the capacity to support the transition. Family Advocacy has just been involved in a campaign around a supported living fund, which we have been successful in. We have had multiparty support for next year commencing a supporting living fund. It will be monumental. It will be the very first time in decades in New South Wales that a person with an intellectual disability will be able to move out of the family home and establish their own home with a combination of informal and paid support without the families being in crisis. We think that that is the kind of way to move. We will be happy to talk about that further.

Senator BOYCE—Could you talk a bit more about the supported living fund and how that is going to work?

Ms Epstein-Frisch—We think it is very exciting. The way in which our system has worked is that people have been rewarded and encouraged to go into crisis. People who are, say, my generation—families in their forties and older—were taught that the service system will you provide with the answers and that you should wait and get services et cetera. They have been taught to give up important family authority and decision making to a service system. That has immobilised them in their capacity to plan. How can you plan when so many of the answers seem to be completely and absolutely outside of your control?

This is all about encouraging families and then rewarding them for taking back that family authority to say, ‘We can envisage and we can work towards having our son or daughter move out of home in a timely fashion—between, say, 18 and 40 in the normal course of life events.’ We as an agency have been doing workshops, information sessions and teleconferences around supported living for a number of years. One of the first things about that is helping people to build their own capacity to plan for the future. When the whole thing rests on the shoulders of mum and dad—and in many families there is just one person; a single parent—it is all too much.

It is about encouraging people. PIN is an example of one of these organisations, but it does not have to be a great big organisation. There should be a network or a group of people who care about the person—and this is building on what you were talking about—rather than care for the person. We are not asking people to look after a person with a disability—the big question—or even provide them with personal care support or go out with them at the weekend, although some of those things do occur. That is not what the ask is about. When you think about it, for the vast majority of us, as we have taken our life steps—our first job, finding a place to live and who you live with—it is about our connections. It is about the people you know—your mother’s sister’s best friend who helped you to get that job.

People with disability, because of the restricted opportunities that many face, have had far fewer opportunities to build those connections. So the first step—and it is a step in planning—is helping the family to bring other people into their intimate circle. It is about saying, ‘I’d like you to help me think about Robert. I’m worried.’ Where we are finding that people are most energised to do it are families where the young person is in late teenagehood. There is nothing like the imminence of leaving school. Other families are doing it at other stages, but there is nothing like the imminence of a point of transition to focus the attention.

Some people have extended families who have always been interested and happy to help, and this becomes the focal point. They are fortunate. Many people, because their lives have been more isolated, have not had the opportunity. When your son or daughter has a disability you are less able to join in local groups and you do tend to have a little less social capital. Then it can require very conscious steps to find one person to help. I can think of the example of a mother who is 82. Three years ago we helped her to form a circle of support. There was one person who came on board. The way she saw it was: ‘There’s a 100 per cent increase in people who are thinking about my daughter.’ Her daughter was in her mid-50s. People need help to think about it. We have all learned to be self-sufficient, not share our problems with others and so on. It is a different way of thinking about it. I can, now or at another point, share some very wonderful stories that come through bringing other people into someone’s family to help them to plan. So that is step No. 1 in terms of the supported living fund.

What it is about then is helping the person with a disability to build some informal support, some connections. When a person with a disability spends all their days in a congregate day program, in all probability they hardly know anyone other than those who have a disability as well and their most immediate family. Building on one of the questions you asked the previous witnesses about individualised care, in the post-school funding program in New South Wales we have options for self-directed support. When people with significant disability leave school, the funding program is called the Community Participation Program and there are three options. There is a centre based option, there is an individualised support option and then there is a self-managed option which is completely self-directed.

The people who are involved in the self-directed option in particular—although this also includes some who chose the individualised support option—are getting out there. These are people with significant disability. I am not talking about people with a moderate disability for whom all these things would be easier anyway if they had a certain mindset. People with significant disability are getting out there and doing real things in the community. They are volunteering. They have little personal businesses. We all laugh about waiting for tradespeople. I know someone who has developed a little business where you can book him to come and wait at your place for the tradesman to come. He has a business that is much sought after. He is using his government funding. Instead of being stuck with another dozen people with disability, he has been bringing in a little bit of income and doing something that you will really value.

That is a part of building informal support because people who have used that business then think, ‘Isn’t that interesting’, and you start to build some connections for people. None of this is quick fix, I think that is the really key thing, it is a journey over time. What the supported living fund will have is that families do some planning, demonstrate some informal support and they will be able to apply to government. I am sure they are going to muck it up initially, you know how these things go, but they will be able to apply to government for funding for paid support that will be used to complement the informal support. When you have to use funding that is determined often that drives out that informal support. It is used for something and then cousin Trudy thinks there is no point in her being involved et cetera. You have paid support that can actually be used such that the family and friends can do this and that, but you absolutely need help with A, B and C and you can decide that you will use that paid funding for A, B, and C.

How do you get housing, the bricks and mortar? Without any doubt in New South Wales it is a challenge. Some lucky people will be able to get it through community housing. We are actually actively suggesting to people when their family member turns 18 to get on the list for public housing. It might be 10 years away but you have to be in it to win it. We tell them to tick community housing which is much better than housing estates where there are a lot of disadvantaged people living together and there is not a lot of social capital there. Community housing which is much more integrated into the community is a better approach. Other people will use Rentstart, there are both Commonwealth and state rent assistance options. Some people will be lucky in that there will be grandma’s flat or something like that or people will have saved and put money away. What many people with disabilities do in this situation is that they might get, say, a two-bedroom place and the person with a disability lives with a person without a disability. The person without a disability provides companionship, a sense of ordinary life and emergency backup support. Then you have paid support to come in and assist the person in the ways that he or she needs.

It is something, we are saying, that still needs high-level planning at the state level. All our political parties have committed to implementing something like this starting next year—

Senator BOYCE—Will this be a pilot?

Ms Epstein-Frisch—No. It cannot be a pilot. It is ridiculous. What we have said is that it should start small. We have said 50 to 100 people in the first year and put some action research around it so that we learn as we go. Over time we will be increasing our expertise about how to use paid support to complement informal support, how to support people to direct their own support and what have you. There needs to be a high-level kind of committee of all the stakeholders to actually work out the implementation and what have you.

Senator BOYCE—With the circle of friends or support circle—whatever you call it that supports the individual in this situation—how do you sustain the circle? What are the mechanisms?

Ms Epstein-Frisch—Once again there is no easy fix. I am Jewish, and I am actively involved in the Jewish community and there is little project that we have had going there for about four to five years, a circles project. It is tiny. It has grown. We got funding from within the Jewish community, so it is not funded from government. There are eight families who are assisted to plan. Last year we spent $8,000 on eight families over a full year. That provides for a coordinator and some very part-time sessional facilitators. It gives us the opportunity to select different facilitators. It is nobody’s job but there are a lot of people who have that kind of knowledge, skill and empathy who are very happy to be involved.

So what that does is provide someone external to the family who works with the family to facilitate—to perhaps get it started, to do that initial ask and to facilitate the meetings. Sometimes the meetings are once a month and sometimes they are once a quarter and what have you. There are circles that go, and so PIN and PLAN—PIN is an organisation in WA—provide some paid facilitation to help. I think it is useful. There is no doubt that it is useful. It is someone outside who helps to keep us on track. ADHC, a couple of years ago, funded some planning pilots—that sort of thing—and each worker worked with 20 people over six months and what have you. It just does not recognise what families are really like.

Senator BOYCE—That was for six months?

Ms Epstein-Frisch—Yes. They would come in and go out—‘We’ve done our plan.’ With the families in this little circles project, there are people: there is someone whose son was in a blocked bed in respite and was a very long way from family and community over a number of years. First of all, it takes quite a long time for parents to come to it and say, ‘Yes, I’ll give it a go,’ because it is a scary idea to invite other people into your life. Then you need a whole lot of time and talking and what have you before you get into the big issues. So the first steps that these circles have taken have been about introducing other people into a person’s life and having them invited for lunch or to go out to the park, the footy or something like that. Three of the circles, after about three years, have now done five-year plans, but it has taken that time to get to the big issues and what have you. Whilst this project was initially conceptualised for older parent carers, in fact only one of those people has stayed with it, because it is a different mindset. This is the woman who is in her 80s and whose daughter is in her 50s. From that one person, it has now grown to about four people in the circle, and they are dealing with the big issues.

As I said, the people for whom it has had greatest resonance are those in the late teenage or early adult years. But it is really important that it is independent of service provision, because it is about how this circle is a mechanism to stand beside the person with a disability and partly negotiate the service system and partly build that informal support and safeguard that person. One of the saddest stories that I know is about understanding of security. When people think about planning for the future, most people think about financial provision, wills and what have you. Those things are important, but the most critically important thing is relationships. In fact, if you see some people and the way they leave their estate and everything to the person with a disability and then the siblings are alienated, they can be doing the worst thing, because that person with a disability needs, perhaps more than anything else, the support of siblings who will care and think about them. It sounds like a blanket statement, but they are really critical things.

This is the sad story. At Family Advocacy we do not take on cases and open files about people, but lots and lots of people ring us for advice with particular issues and we help them to solve those issues themselves and to take steps. There was a call a couple of years ago from a father in his 70s who had been one of the founders of a very major service provider in New South Wales and had been on the board for many, many years. He and three other parents had used their own money and bought a house that their sons and daughters were to live in into the future et cetera, and that house was in the name of the service provider. It is not a bad service provider, but they have grown and developed and they actually do not provide accommodation anymore, and the only house they had was this particular one. Here the man was in his 70s, when he would have hoped to be feeling a little bit more secure for the future, and the service said to him: ‘I’m sorry, but we can’t; it’s just not consistent with our future planning. We’re not going to be providing accommodation support anymore. Your son now has to go and live somewhere else.’ This poor man had devoted himself to this, because he had seen the safeguard of a service, whereas for a safeguard he would have done better to invest and have the money and the house in his son’s name. There are those things that really attach to the person or the people who really care about that person.

Senator CAROL BROWN—Is that what you mean when you say in your submission that the disability service system has in fact created dependence in families and thwarted family initiative and planned?

Ms Epstein-Frisch—Yes, those sorts of things. As the previous witnesses talked about, the pathway to accommodation is crisis. If you know that the only way you can get your son or daughter to move out of home is if you have fallen to pieces, that actually accelerates your sense of being out of control of such important things in your life. I have quoted in the submission some fantastic epidemiological research about the impact of lack of control or the impact of control on people’s wellbeing, longevity and that sort of thing. On that key issue of who will look after your son or daughter when you die and where they will live, families having no control over those things impacts negatively on their wellbeing. If people think they can only have their son or daughter move out of home when government has given them all the resources and the package, that inhibits them from moving forward. And we know that for most people the kinds of resources they are going to get from government are not necessarily what they dream of—a bed in a place, smiles from family and community—but people who are strangers and who have their own challenges. That is not what they would dream about.

Senator CAROL BROWN—You have also indicated in your submission that the New South Wales government has embraced person centred planning but has failed to move structurally to underpin that. Can you talk about that a bit more.

Ms Epstein-Frisch—This happens so much: you take on the language and the practice stays the same. They are giving workshops and what have you about putting people in the centre of service provision. They are good people. They are good ideas. But in some ways it was probably more honest when workers were working towards an individual service plan that said, ‘Within the constraints of my organisation and the funding I get for a particular program area, I am struggling to work with you to do what you want.’ That was an honest, genuine and good thing. If you are really talking about person centred planning then that is: ‘I’m living in a group home and I’d really like to live near the beach, thank you very much,’ or ‘I’d like to live at least in the suburb where my cultural communities or my family is,’ or ‘I love gardening and I’m much less agitated when outdoors, so for my day program, I’d really like to do some bush care and there’s somebody I know I could do it with.’ So they have not thought through what it actually means to have person centred planning when you were running a day program.

Senator BOYCE—Because they can’t deliver it, is what you are saying.

Ms Epstein-Frisch—Yes, and maybe it is just more honest. You cannot even have a discussion because people say they are doing it. They have got ‘person centred planning’, and you water the garden at the day program. There are a few things that have to go with person centred planning and self-direction.

Senator BOYCE—Tenpin bowling?

Ms Epstein-Frisch—I was thinking more that you have to build the vision of people with disabilities and families. If you have only thought that you just do tenpin bowling, movies, group coffee shop or lunch in the park, it is hard to imagine that someone could actually do bush care or have a little business delivering mail. If you actually give families the opportunity to go to some seminars or conferences or what have you where they hear of people they can identify who describe sons and daughters who are just like their son or daughter, then they think, ‘God, if they can do that why can’t I?’ It is about having a different vision. We need, firstly, to be doing that and, secondly, to help the service workers have a different kind of vision and some different training. What we are emphasising is certificate III and IV disability training.

If you need manual handling, a person who has high physical support needs, that might be useful. I am old-fashioned. Back in the eighties, we had SRV—social role valorisation—training, which was about understanding the devaluation that people with disability faced and putting in place strategies and actions that gave people with disabilities real roles and the opportunity to form real relationships because they were the safeguards and they were the things that were much more likely to give them a good life. So we really need to rethink this. Person-centred planning is about, firstly, building capacity and vision of people with disability in families, secondly, about different kinds of knowledge and skills for staff, and, thirdly, as an organisation: how does my organisation need to change if I am putting people in the centre as against my service? It has to, surely. I do not think that they understand that or have a commitment to implement it.

Senator BOYCE—Are you aware of the concept of microboards and can you tell me anything about it?

Ms Epstein-Frisch—I cannot tell you a lot.

Senator BOYCE—Have you seen any established?

Ms Epstein-Frisch—No, but I have read about them. In WA they have some. WA is a place to look to for many things.

Senator BOYCE—We have had some—

Ms Epstein-Frisch—You have been there.

Senator BOYCE—We have not been there, but we have spoken to them, haven’t we, Senator Siewert?

CHAIR—We did it through teleconference.

Ms Epstein-Frisch—The whole concept is about a small group of people who get some authority to plan and support an individual to have a good life, and that is a good thing.

CHAIR—The thing I found attractive about the microboards is that if you are coming off, there is a place there and you help find somebody that goes on, that is one of the concepts.

Ms Epstein-Frisch—Yes.

Senator BOYCE—So it has an inbuilt sustainability, one hopes.

Ms Epstein-Frisch—Absolutely.

Senator CAROL BROWN—Like the circle of friends concept.

Ms Epstein-Frisch—Indeed, only a bit more formalised.

CHAIR—It is a bit more formal.

Ms Epstein-Frisch—It is called different things. The concept is about a group of people who are thinking about John; not thinking about people with disability as generic, but are thinking about the individual.

Senator BOYCE—One thing we have found is that when you are starting to talk about that sustainability of long-term planning, a lot of people have not quite thought that through. I am of the view that the only thing that will ever keep a plan sustainable is the circle, a group of people who care—whatever you call them. Would you like to comment on that?

Ms Epstein-Frisch—I agree with you. And succession planning is critical. Say you have a person with a disability in their 30s and you have a circle that is made up of the parents and the parents’ friends in their 60s, it is going to run out of huff. There is a really important role—and no-one pretends any of this is easy—in bringing in people of the right age, and then there is the next generation as well. And who you would talk to who has done lots of thinking around these things is a little organisation in Queensland called Homes West. I do not know if you have had anything to do with them.

Senator BOYCE—Pave the Way are coming to give us evidence tomorrow.

Ms Epstein-Frisch—Fantastic, because they will talk about this. It is succession planning. They talk about it as practising dying.

Senator BOYCE—You made the point about WA being—I hate to say this in front of Senator Siewert—the place where all the innovation in this area is coming from at the moment. Is that a cultural thing, or is it just serendipitous?

Ms Epstein-Frisch—No, I do not think it is serendipitous. Although I have not been there—I have been there a few times and talked to people—it is more what I read about and what have you, and I have some colleagues. A really critical thing there was that in the 1990s, or maybe it was the late eighties, they developed their local area coordination program. The background to that, which some of you may or may not know, was that adults with disabilities—compared to us, their rural and remote is really remote—would come down to Perth to live in institutional care. And so a group of people—it was a small number at the start, social work type people—who had money in their back pocket, flexibility, went out and met with people in remote areas and said, ‘What would it take to enable you to stay in your family or in your community?’ Therefore, one by one, they had a community development approach that was about building informal support and using paid support to complement that, instead of having, ‘Well, you’ve got your post-school funding.’ What does that mean in outback somewhere or other?

Senator BOYCE—Pick a town, Senator Siewert!

CHAIR—Indeed! Well, anywhere!

Ms Epstein-Frisch—Indeed. So it was really very flexible. Now we have something, and many states are developing iterations of local area coordination, often doing some very odd things in it. From what I understand, one of the key things was that, whilst the local area coordinator was a public servant, a government employee, they did not work from government offices; they were in the neighbourhood centre—they were of the community.

CHAIR—Because I have travelled around Australia, that reminds me that there is less angst—although there is angst—between government and nongovernment.

Senator BOYCE—In Western Australia?

CHAIR—In Western Australia, yes, and that is across the board. We—government and nongovernment—still fight like cat and dog, but not the same as they do in the east. I have noticed that.

Ms Epstein-Frisch—We are really good at it—

CHAIR—We are still good at it, but—

Senator BOYCE—If you could pin down a reason for that cultural difference, that could assist as well.

Ms Epstein-Frisch—Maybe it is because the distance is bigger, there are perhaps less resources and you just have to be sensible for people. If you can get that through rather than people thinking about the best interests of their service or their system—I do not know.

Senator BOYCE—You made the comment before that long-term planning takes time, and yet for a lot of parents there is not a lot of time to get this fixed. What are your thoughts around how we assist that group of people to try and have some calmness—serenity, I suppose?

Ms Epstein-Frisch—I do not know that you can get serenity, because you will not be able to magic things up quickly. I think it is continuity. It is having someone identified who will help them to plan then, who is not going to get another job in six months time—and they are all the problems et cetera—and who will help to go at that person's pace. Even though the people might be in their 80s et cetera and their pace might seem, to you and me, much too slow, unfortunately there will be little crises that will force their hands and make them. But you have to build trust. I do not pretend to have great expertise. I am probably stronger on building the preventative infrastructure that reduces the number of people in 20 years time who are in that scope than able to give you any kind of quick answer, but it is continuity and trust.

Having a look outside the service system is interesting. It is about having the service system able to think laterally, and it does not. Someone rang about his brother, living with the elderly parents. The government service system had told them that he would have to get out, move out of that home, be on the wait list and all that sort of stuff, whereas the parents were absolutely happy that the family home would be the brother's, and the brother was happy to forgo his sense of the inheritance. So he has bricks and mortar. If he could have somebody else come and live in there and provide some of that just-in-case support, you could use the paid support to come and drop in and do what he needed. It was not so hard, but the service system thought, 'Oh, no, we need to do X, Y and Z and it's got to be in a special place.' How you put a bomb under people's thinking is really—

CHAIR—That is not the first time we have heard a story like that either.

Ms Epstein-Frisch—I have an answer to a couple of the things that you asked the previous people that I would just like to make a little comment about.

CHAIR—Go for it.

Ms Epstein-Frisch—In terms of early ageing, ageing in place and what happens, I will talk about my daughter, who is 26 and has cerebral palsy and very high physical support needs. She is a lawyer. She works. She is a very capable young woman. She lives in another city from me now, lives with some friends and has drop-in support. She receives a government package of 35 hours of personal carer support each week. When she is 65, if she is forced into the aged-care sector, she will be in a high-needs nursing home. That is the response. So their top-level EACH packages, 20 hours, just will not cut it. In terms of that interface, her needs will not decrease.

Senator BOYCE—We have had some encouraging words said about how perhaps some of the empowerment and flexibility of the disability rhetoric, anyway, should be moved into the aged-care sector.

CHAIR—At the moment, under the current system—certainly this is what we heard in Victoria yesterday—the package that somebody has under disability funding disappears when they go into aged care. It is only when you are—what was the language we were using this morning?—not the squeaky wheel but noisy, stroppy and cranky that you manage to achieve some sort of carryover. But unless you are noisy, stroppy and antagonistic in many cases—

Senator BOYCE—Assertive.

CHAIR—assertive, I should say, yes—you do not get it.

Ms Epstein-Frisch—Absolutely. And the other thing is around self-directed support, what Michael was talking about around attendant care. An excellent evaluation was done by the Social Policy Research Centre that might be worth looking at around the Attendant Care Program. In New South Wales there are three options. One is using a service, as Michael has said. One is using a financial intermediary. There is an organisation called Allowance Inc. which actually provides the legal and financial mix. It helps people meet their legal and financial responsibilities but allows people to employ their own attendants, train them and use them in the way they want. And then there is direct payment, which a small group of people are on. In the evaluation, people using the financial intermediary and direct payment were just better on every single one of the things that were being examined by the evaluation.

CHAIR—Is Allowance Inc. in New South Wales?

Ms Epstein-Frisch—It is in New South Wales, but they do support people in other states as well. I know certainly of some people in the ACT.

CHAIR—So you could go to them and say, ‘I want you to manage my son or daughter’s package.’

Senator BOYCE—They are doing the bookkeeping aspects?

Ms Epstein-Frisch—They are doing the bookkeeping, the reporting to government and what have you. People get better value for money. They take less money. You can thereby get more hours.

Senator BOYCE—One of the concerns about individual self-directed funding is about that hiring and firing and understanding your obligations et cetera. People are quite concerned about having to do that.

Ms Epstein-Frisch—And most people do not want to become a service provider to do those kinds of things.

CHAIR—Or set up a company—

Ms Epstein-Frisch—Absolutely.

CHAIR—which is what our mob in Albany have done in WA. They have set up a microboard to do that.

Ms Epstein-Frisch—Yes. So I think probably the financial intermediary will be the key for many people in going forwards. Certainly in New South Wales, in our advocacy around getting more self-directed support, we are saying that you absolutely need to give people and families support to get the opportunities out of it, because most people have not thought it through and need assistance. But we are arguing that that assistance needs to be independent of service and government. It is kind of standing beside the person and thinking about their best interests and how to make it all happen.

In our discussions with family, we do not pretend that it is easy. None of it is easy. It takes time. It takes effort. It is relentless. But we suggest to people that, when you have your son or daughter in a group home and things are going really badly and no-one is addressing those issues, that ain’t easy either. At least this is a positive kind of movement. We do not put it as an easy thing about which you can say, ‘That’s settled; that’s done; we can get on with the rest of our lives,’ because there continue to be lifelong issues of support.

Senator BOYCE—You have basically made the point that the disability service system has groomed families to be dependent, to accept what they are given, not to think outside of the box et cetera, but at the same time that system has almost taken as a given the idea that families and parents would look after the person with a disability until they could not do it any more. We are talking about an enormous cultural change to move people from that. What are your ideas and suggestions around that?

Ms Epstein-Frisch—In New South Wales we are about to launch a campaign for our state election about getting self-directed support. You do not have trouble getting people with disabilities and families to understand and want to have greater control over the what, when, where and by whom of support. Even people who have been quite happy in their group home or their day program or their individual whatever can always think, ‘Gee whiz, if I could choose the person, I would choose someone a bit different to that. If I could choose when the help came, I’d do it a bit differently to what I’m getting.’ It is about having significant influence and deciding: ‘Look, I really need someone to come at 6.30 in the morning, not at nine o’clock,’ and those sorts of things. It is not too hard. Particularly when you can help people see how it makes life different and better for them, it is not that hard to get families and people with disabilities on board wanting it, but they need help to implement it. What is really important is to give the message: you do not have to do this. This needs to be an option in the service system. We keep our services, but this is an option. We would argue that, over time, as people see it in other people’s lives, people will like it and more people will move to it. We do not want to just shut down services—not at all.

The other place we look to is Victoria. In Victoria, in 2008, they had a monumental change. First of all, they broke down the silos and people knew how much money they could get. That was monumental. Then you could choose to stay in your service or you could move to another service. The second option is that you could have your money from the respite bucket and the post-school bucket and the whatever bucket paid to a financial intermediary who would look after the financial and legal things and you could decide how you were going to use the money. Everyone now has access to direct payments, where you can establish a new bank account and have the money paid into it.

Senator BOYCE—Mind you, we were told in Victoria yesterday that you needed to aggregate three or four people’s direct funds to have sufficient funds to buy meaningful services.

Ms Epstein-Frisch—It depends. When you have it individualised, if you are looking to translate it all into one-to-one support, then, yes, you do need that, and then you are grouping people. The whole basis works on this: with individual funds you are using it to build some informal support. For example, if I have my two hours of funding and I use it on a Saturday to go bowling, that is good fun and I have a nice time. At the end of it, with my paid friend, what do I want? I want another two hours. If, on the other hand, that support person helps me to join a bowling club, ultimately I am getting more of the support I need from the other bowlers. The paid support person can slowly edge out of it and I can go bowling on Saturday without the paid person and they can help me start Italian classes on a Tuesday evening. That is where the knowledge and the skills are required. We use it as just a velcroed person. Always having a person there can get in the way of forming relationships—‘I don’t need to talk to you. You’ve got your own friend.’ That is the kind of values based training, knowledge and skills that we need to impart if we are going to get something out of the self-directed support. Once people start putting it all together and having three or four people, because they still think, ‘I need 35 hours paid support,’ you would be back to your group home and saying, ‘I’m not getting what I need because I have to take into account Tom, Mary and Sue. My parents might get on well, but I have never really liked Sue.’

CHAIR—We are over time. Thank you very much. Your evidence has been very much appreciated.

Proceedings suspended from 2.50 pm to 3.00 pm

BELLCHAMBERS, Mrs Joyce, Secretary, Dare to Care

CRADDOCK, Mrs Marie, Manager, PATH Inc.

NOLAN, Ms Joan Estelle, Member, Management Committee, PATH Inc.

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

Mrs Bellchambers—Yes, I have.

CHAIR—We have your submission, which is No. 19. I invite you to make an opening statement and then we will ask you some questions.

Mrs Bellchambers—Dare to Care is a subcommittee of PATH Inc. I would like to thank you for inviting me to this inquiry. Dare to Care is a disability advocacy organisation. We are a very small group who are concerned with the needs and rights of people with disabilities in the Nepean area, which includes Penrith, the Blue Mountains and the Hawkesbury. We are particularly interested in respite and supported accommodation in those areas. We were formed 13 years ago, and we find that supported accommodation is still in crisis. Both Dare to Care and PATH commissioned Lynn Houlahan, a psychologist researcher, to do some research. She found:

> Given the strongly identified need within this report for a greater range of supported accommodation choices, it is crucial that further options be developed and made available to people with disability and their carers.

I would also like to talk about my own story, if I may. I am 83 years old and I care for my son who is 54 years old and has a disability. He has psychiatric as well as intellectual needs. He also suffers from agoraphobia; therefore, he cannot leave the house. We have respite care but, unfortunately, he will not leave the house so it is quite meaningless to have the respite care in the home. I do not see any other options at the moment.

I fear also what will happen to him when I am no longer here. What plans can we put in place for him? I personally have the idea that he should age in place and age in his own home, with informal or perhaps formal care. I do not know where that care will come from, but it has to come from somewhere because of the time limit.

CHAIR—Would you like us to ask questions now?

Mrs Bellchambers—You can ask questions; I will see if I can answer them.

CHAIR—Have you said everything you want to say? We are more than happy for you to continue.

Mrs Bellchambers—I do have a little bit to say about funding, and there is also another Dare to Care person who is a very good speaker but she had a sad bereavement in the family; she lost her mother. She is an excellent speaker, and you have got me.

CHAIR—You are doing pretty well.

Mrs Bellchambers—She would have been here today, and I am sorry she is not. She has a daughter of 30 with Down syndrome, and she has been searching and searching to get an appropriate accommodation placement for her, and she cannot see that happening. She is very well informed about disability services and things and holds quite a good job in that respect. To date she has not been able to find anything for her daughter that is appropriate. The girl is quite active in day programs; she is unlike my son.

Senator BOYCE—How long has she been searching for appropriate accommodation for her daughter?

Mrs Bellchambers—She has been searching for at least 13 years, since Dare to Care began.

Senator CAROL BROWN—How old did you say her daughter is?

Mrs Bellchambers—She is 30 and she has Down syndrome. But she is a very active little girl and she does quite well, considering. She is very sociable. She is different from my son. She can get about and socialise. She does ballet and all sorts of things like that. But having a psychiatric disability as my son has, it changes things completely. It is very difficult to get anything for him.

CHAIR—In terms of accommodation and support services?

Mrs Bellchambers—Yes.

Senator CAROL BROWN—And her search for accommodation is just in the area that you service?

Mrs Bellchambers—Yes, she wants to be near to her home, if she can possibly do it. Everybody likes their family to be close. I know I like my family to be close. As I say, families are desperate for supported accommodation and there is such an ageing phenomena that it is getting worse and more critical. It is almost impossible, actually. I know another lady whose son has a dual diagnosis and she had to relinquish him. That is not appropriate anyway, but she had to accept it. Then she has to go to the guardianship tribunal because she did not want to accept the accommodation at first. They are testing her capability to look after him.

CHAIR—She would not accept the accommodation that she was offered?

Mrs Bellchambers—Not at first, no.

Senator BOYCE—Who initiated that case with the guardianship tribunal?

Mrs Bellchambers—She did, three years ago. I hope my memory is right. I am relying on it but it is not very good. She and her husband initiated the guardianship because he was under—

Senator BOYCE—They relinquished him and then—

Mrs Bellchambers—He was relinquished just recently into care for three months. He went into a psychiatric facility. But prior to that the public guardian was in charge of him, and then they got guardianship themselves—the two parents. They are still fighting that to retain their guardianship of him. They are going to the tribunal fairly soon, I think. I do not know whether I should mention her case, because she is very sensitive. There are no names mentioned so it should not matter.

The other thing I wanted to talk about was the infrastructure. We must have infrastructure in place for the years ahead to accommodate this crisis. Through the service system, provision of appropriate support accommodation is crisis driven. As I said about this lady, she had to relinquish her loved one because she could no longer care. Accommodation is a basic right under the Convention on the Rights of Persons with Disabilities. I will just quote something from the convention. It says:

> In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

I just say here that governments should work together with families. They certainly must work together in establishing a sustainable plan for the future, and carers need to be well informed as to the process. Early intervention is therefore necessary to make this possible in the long term. During this process, such consideration should be given to the individual and the fact that one size does not fit all. I think everybody is aware that one size does not fit all; it is a cliche, but it does not. Group homes work for some people but not for others. They are therefore needlessly expensive. With self-directed funding, people with disability could make their own choices and not be under the vagrancy management approach.

I mentioned here moving away from traditional funding to self-directed funding. I heard Belinda talking about self-directed funding. I was trying to tune into her. I cannot speak the way she does, but she covered the subject very well. We do need self-directed funding; I do believe that. But it has to be a mechanism to conduct financial management, contracting, recruiting, employment and accountability obligations. Independent monitoring would need to be in place as well.

Building on Stronger Together, the Supported Living Fund would encompass provision of new money, extend the target group to include families not in crisis, enable people with disability to have a home of their own, use a combination of paid and unpaid informal support and enable families and people with disability to direct their own support as endorsed by the New South Wales political parties on 25 October 2010. I started to mention the Productivity Commission, but I have read that we are not to overlap with that.

CHAIR—I think some of the issues that we are talking about will inevitably overlap with the Productivity Commission, but I think we go beyond what the Productivity Commission is doing.

Mrs Bellchambers—A lot of people are waiting on the result of that in order to give themselves peace of mind, especially old people like me. We have to get something as soon as possible—that is what ASAP stands for. I forgot to tell you about ASAP.

Senator BOYCE—I did not forget that that was what it stood for, but I was a bit interested to see that the ASAP Project started in 2004.

Mrs Bellchambers—Yes. So it is not very quick, is it?

Senator BOYCE—No, it is not terribly ASAP.

Mrs Bellchambers—Lynn is the psychologist, and she has a lot of degrees, and she did a good job on that, I think, especially for our area. Do you want me to read out a few of her findings or not? They are all in there.

CHAIR—They are all in here, aren’t they?

Mrs Bellchambers—There is a perception of bias and prejudice within the community against persons with disability, and some carers felt their lives would be empty without their family member. I would be empty without my son living with me. I love having him with me. Unfortunately, we will have to part in the future—not too soon, I hope.

Changes in case management and staff and burdensome assessments are unsettling for carers. I could not tell you how many assessments I have had to do for every single person who has come into the house from different services. Even though it is for the same thing you have to go through the same assessment all over again. It is a pain in the neck. I have struck poorly trained or inexperienced staff in supported accommodation and possible abuse through lack of supervision and monitoring. My son was sexually abused in one accommodation service, which was not very nice. There were poor food choices, nutrition and access to transport. Ability to access psychiatric inpatient services was seen as a high priority.

Senator BOYCE—Thank you, Mrs Bellchambers. As I said before, your ASAP project was an excellent initiative, but—

Mrs Bellchambers—It is old.

Senator BOYCE—You mentioned July 2005. What has since come out of the project?

Mrs Bellchambers—We have worked on it. Dare to Care have followed up as much as possible. We have put in submissions and lobbied governments, both federal and state. We get a very good reception, but nothing has happened. We have done a lot of lobbying in order to put our name on the map, but to date nothing has happened. It proves that there is no accommodation readily available unless you relinquish your children.

Senator CAROL BROWN—Unless you create a crisis.

Mrs Bellchambers—Yes.

Senator BOYCE—Does ‘relinquish’ have a legal definition? What do you mean when you say ‘relinquish your children’?

Mrs Bellchambers—To more or less put them into respite care and leave them there.

Senator BOYCE—It is a bit like dumping them?

Mrs Bellchambers—Dumping. You can leave them at the police station or the hospital too, if you choose to.

Senator BOYCE—You would have to be in absolute crisis to do that, wouldn’t you—and I am sure people have been.

Mrs Bellchambers—They have done it—there is proof, though I do not have it with me now—and I can understand why. They are exhausted and cannot carry on any longer.

Senator BOYCE—Would it be true to say that one of the reasons they cannot carry on any longer is that there is no hope of something coming up in a week or a month, for example?

Mrs Bellchambers—I would say that would have to be the case.

Senator BOYCE—You have said that governments must work together with families. I would think that your view is that that does not happen right now. What should happen so that governments and families can work together?

Mrs Bellchambers—They should meet with each other, have forums and be accessible. Also, it is important for governments to know and understand more about disabilities—there should be more awareness. I have met with some people in government and they really do not understand disabilities. I know you people do; that is why you are chosen; but others do not. You have to educate doctors also.

Senator BOYCE—That is sort of the idea behind the carer or parent—in most cases, the mother—being an expert advocate for their child, isn’t it?

Mrs Bellchambers—Yes.

Senator BOYCE—One of your aims in preparing the ASAP Project was, as you said, to try and come up with a workable solution in the event that you cannot provide the care any longer. Is that the aim of all the members of Dare to Care?

Mrs Bellchambers—The ASAP Project was mainly to identify just how many people were out there and what kind of assistance they needed.

Senator BOYCE—You found 27—is that right?

Mrs Bellchambers—Yes. We know there are more. You cannot identify a lot of people. They do not want to be identified, sometimes, I find.

Ms Nolan—Not till they are in crisis.

Senator BOYCE—Why is that, would you think?

Mrs Bellchambers—I cannot understand that. Surely Centacare and all the respite services should be aware of them. All the statistics should be aware of them, but you cannot get access to them through that, through freedom of information.

Senator BOYCE—It is not that they are not known to the disability industry, for want of a better word, it is just—

Mrs Bellchambers—Yes, they are probably going to workshops and to day programs.

Senator BOYCE—We have had evidence already that there are some people who might be known to the federal system but not to the state system, and vice versa. Perhaps there are people who have no contact whatsoever with the federal system until they want to retire from work, in a disability enterprise or something like that.

Mrs Bellchambers—There will also be the age phenomenon in 2012 because COAG changed the rules. The state will take care of people with disabilities up to the age of 65 and the federal government will take care of them after 65, but that will not be in place until 2012, I think.

Senator BOYCE—That is the plan. Some people have expressed concern about that. They are concerned that gaps will develop between what the states do and what the federal government does. How does Dare to Care feel about that?

Mrs Bellchambers—To be honest, I cannot answer that because we have not discussed it. I am only speaking for myself on that. I will have to take that question on notice, I am sorry.

Senator BOYCE—That is fine. What about long-term planning and sustainable long-term planning? Any examples you would like to give us would be fine, even if you just want to say what you hope will happen in your case.

Mrs Bellchambers—I am hoping that I can leave my home to my son and have the appropriate care come into the home, whether it be formal or informal or care share. But there are legal implications and restrictions there. You cannot look into the future and know what people will do, but that is what I would like.

Senator BOYCE—Your son would own the home?

Mrs Bellchambers—Yes. The care would have to be well monitored, of course, and screened.

Senator BOYCE—Who would you see doing that?

Mrs Bellchambers—With the self-directed funding or the self-supported living fund, if there is money there that could supplement the second phase of Stronger Together and provide money that way. I am not into the circle of friends, like Family Advocacy are; I do not know too much about that, but it sounds like a good idea. There would be money available to him from my estate in order to help towards his lifestyle.

Senator BOYCE—So you would see a financial intermediary perhaps running the care funding for him?

Mrs Bellchambers—Yes, you would have to have a financial intermediary for sure.

Senator CAROL BROWN—I was just having a look at your ASAP research and it is obvious that people have various needs. They are not all the same and I suppose they would be needed at different stages of their lives. Some are about accommodation, some are about respite, some are about day programs.

Mrs Bellchambers—Yes.

Senator CAROL BROWN—But, reading your submission about planning, it is Dare to Care's view that it is not much use planning for the long term when there is no appropriate accommodation in your region. Is that correct?

Mrs Bellchambers—That is my view and it is the view of the ASAP Project, because it does not give you much hope when there is nothing available. That is all. So what do you do?

Senator CAROL BROWN—That's right.

CHAIR—That is what we are trying to work out.

Senator CAROL BROWN—That is what we are here to look at.

Mrs Bellchambers—Jump up and down? I am sorry—I may not have answered that very well.

Senator CAROL BROWN—Does Dare to Care actually engage in planning? Do you assist members with planning?

Mrs Bellchambers—No, to be honest. We are a group of eight. We meet bimonthly and we discuss what submissions are available, what is happening in the government sector and the region or whether we need to have a public meeting. We would dearly like more members. We started off with a huge crowd of people but they were gradually whittled away. In the meantime, just recently, three carers who were originally with Dare to Care have passed away, which makes it very pertinent that I am here today in order to put my story across. They were primary carers and their families are living at home. We talk about all sorts of things like that. Sometimes we talk a lot of nonsense too!

Senator BOYCE—Heaven forbid. Just like the Senate!

CHAIR—No, they could not possibly be as bad as the Senate.

Mrs Bellchambers—We have a very good cook and she makes some nice afternoon teas.

CHAIR—You all have similar sorts of issues around not being able to find accommodation. You are getting older as well and your children are getting older. So, of the group that you have identified in your area who are in need, how many would be getting to crisis point?

Mrs Bellchambers—There is one, to be honest, at the moment, to my knowledge.

CHAIR—And when we say ‘crisis point’, that is when they need to find accommodation for their child now?

Mrs Bellchambers—Yes.

CHAIR—What is the time frame for you? You would like to make sure arrangements are in place for your son over what sort of time frame so that you feel comfortable that you have things in place for him?

Mrs Bellchambers—If it was something that really suited him, I would want something for him as soon as possible so that I could see where he is and organise a transition period. He is on the register, and has been for six years, but nothing suitable has come up.

Senator CAROL BROWN—No offers?

Mrs Bellchambers—We had one offer, but it was such a long way that I could not cope with the travelling. Also, so many institutions are devolving at the moment. They are all getting priority for the vacancies anyway, because it is government policy that they devolve. So where would my son fit in? Out of 2,000 people in institutions, they have only found 384 places, so for anyone in my position there is no hope.

CHAIR—When you say ‘institutions’, which institutions do you mean?

Mrs Bellchambers—I am talking about Freemans Reach, Weemala, Lachlan, Grosvenor. Grosvenor has already devolved. I do not have a list of them. I should know them all.

Senator BOYCE—It does not matter. We have got the government coming soon.

Mrs Bellchambers—Peat Island is the other one. That is already devolving. Out of the 31 institutions, I think they have devolved three.

Senator BOYCE—So you are saying there are 28 to go.

Mrs Bellchambers—No. Seven of those are ADHC owned. There are 21 to go, actually.

Senator BOYCE—Is it the case that it has always been difficult to get supported accommodation and that it has always been crisis driven supported accommodation?

Mrs Bellchambers—Yes.

Senator BOYCE—Or even in group homes?

Mrs Bellchambers—In 1984 my son was readily accepted into a hostel, Cherrywood Village, where there were 42 people. It is called a hostel but it is still care. He was accepted there in 1984, so it was not so bad then. But then they brought in the referral and intake management, which made it harder, I think, to get anything. You could not just go to a private group home or service and say, ‘Do you have a placement for me?’ You cannot do that. You have got to go through the referral and intake management committee.

Senator CAROL BROWN—What year did you say the intake and referral system came in?

Mrs Bellchambers—It came in in 2003, I think. Maybe I should check that out. I do not like quoting figures and lying to you.

Senator BOYCE—Again, surely the government will be able to tell us.

Mrs Bellchambers—You will have ADHC here, anyway, soon. Will I be able to sit through and hear what they say?

CHAIR—Yes, of course. It is a public hearing.

Senator BOYCE—You said that your son had a psychiatric disability, Mrs Bellchambers.

Mrs Bellchambers—Yes, he has.

Senator BOYCE—Are there any extra services or different services that you feel you would need because his disability is psychiatric rather than physical or intellectual?

Mrs Bellchambers—Sometimes I feel he needs to be in a nursing home, actually. Because of his mental illness, all he does is lie down and sleep through the day. He does not fit in. He does not like crowds. He is slightly autistic, and any noises are very distressing to him—for instance, if there is a sudden noise such as a child screaming. Otherwise, he is on medication and he is very manageable. The medication does make him sleepy, but he did that anyway, even when he was not on it. He has been on Modecate and stuff like that for a long time—many years. He has been on all of that since 1977. It was administered by injection at first, but now, fortunately, he is able to take medication orally. I watched him for 23 years getting that awful injection of Modecate and I could not bear it any longer, so I asked a psychiatrist whether he could possibly give him something that is a little less invasive. We have hit on something that is quite good. He just watches TV. He likes to read. He can read and write, which is good. He is very manageable. He is a beautiful person.

Senator BOYCE—You are talking about the Penrith-Nepean-Blue Mountains area. Do you feel that there are any particular issues for families in that area as opposed to, say, families in urban Sydney?

Mrs Bellchambers—I might have to call on Joan. She lives in the Blue Mountains and might be able to fill you in on that.

Senator BOYCE—Joan, do you see any particular issues in the Nepean-Penrith-Blue Mountains area that are distinctive from those in urban Sydney?

Ms Nolan—I suppose the Blue Mountains is blessed in a way in that there are a number of group homes run by very reputable governing bodies. I am not the one you should be talking to, because my friend at the back, Maria, is the current manager of PATH and has much experience in the Blue Mountains group homes. I feel that she would have much more valuable evidence to give because she has worked in them for many years. We are lucky to have them and we are also lucky to have so many reputable bodies conducting them, but there are probably quite a few quite severe issues just the same. Maria would be able to tell you about them. She has first-hand experience.

Mrs Craddock—What was the question?

Senator BOYCE—Are there any specific extra needs or differing needs in your area compared to those of families in urban Sydney?

Mrs Craddock—Families in urban Sydney would have less travelling to go to day-care centres or attend to health issues and have those things facilitated. In the Blue Mountains you have distance. If you are in a group home you have to have community transport or use Greater Western transport, which provides a pick-up service from private homes and group homes to get people to their day programs. At Katoomba hospital there are not a lot of medical staff readily on hand to understand clients and residents and their issues. They have intellectual, physical and mental health issues. In one group home in the mountains there are seven residents. Two are in wheelchairs, two are mental health care patients and the others have different degrees of intellectual disability. There are the dynamics of them all getting on. To get to psychiatrist appointments or dental appointments, we have to travel to Westmead from Katoomba. If you want to go to Nepean hospital, you have to book in and wait. The health care of the residents is lacking.

Senator BOYCE—Mrs Bellchambers, you mentioned that three of the carers involved in Dare to Care passed away. I will understand if you cannot answer this question, but could you tell us what you can about the care that is now being offered to their adult child with a disability?

Mrs Bellchambers—One of them in particular had two boys, both with an intellectual disability. One is in Rydalmere and the other one is at home. The parent who died was the father, so the mother is now left with the sole care of the boys. I have not actually seen her of late, so I do not know all the details about that. We read it in the paper, to be honest. The other case is two members of Dare to Care who were husband and wife. The wife predeceased the husband some years back, then we read in the paper that the husband had passed away as well. So we do not know what has happened to the son now. We have to go around and see, because it only happened in the last two weeks. We have not got a lot of detail. The other one was the lady who was going to be here, who has the daughter with Down syndrome. Her mother died and her daughter is blind—her sister. So the family will have to come to terms with what to do about her now.

Senator BOYCE—This is the sister of your member who is blind?

Mrs Bellchambers—Yes. The mother died. It all happened in the last two weeks, plus I lost my own best friend just last week.

Senator BOYCE—That is very sad.

Mrs Craddock—Can I make a comment about parents relinquishing their children. I know of one case where the parents just left their son in respite and he went through three different services before ended up with one service provider, and he has come a long way since he has been in their care. I think it has taken three to four years for him to get to that place. They tried everything to get accommodation in a group home for him and the only way they could do it was to relinquish him at that time.

CHAIR—Was that a formal process when they relinquished him or was it a case of leaving him in respite because that was the only way they could deal with the issue?

Mrs Craddock—He used to come to respite every weekend for so many weeks and then one weekend they just did not come to pick him up. It went from there—the transition from one service to another service to another service.

Ms Nolan—If I could add one little thing about a gap. I am in touch with quite a number of elderly parents, in their 80s, who have one child at home and the other partner is deceased. They want to keep that child at home. There needs to be some sort of a regular supportive arm or branch or group that they can turn to when things just get a bit too hard. Two of the ladies I am thinking of are very frail but they are quite happy to have their daughter at home. One has schizophrenia and another form of mental disability. They do not want to part with them; they just want to have more help that they can rely on or can be aware of when things just get too hard for the time being. Ultimately, they will not be able to keep on. If there were some sort of a mechanism in place where some occasional carers were well known to the family, that would be good for when a big crisis comes.

CHAIR—Thank you very much. Your evidence is very much appreciated.

[3.44 pm]

McALPINE, Ms Ethel, Deputy Director-General, Ageing, Disability and Home Care Agency, Department of Human Services, New South Wales

CHAIR—Welcome. I understand information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. As a departmental officer 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 the department's submission, which is numbered 62. I would like to invite you to make an opening statement if you care to, then we will ask you some questions.

Ms McAlpine—Thank you for the opportunity to be here this afternoon to discuss the importance of planning options for people who are ageing with a disability. The New South Wales government understands the critical importance of future planning and support services for this cohort of people. I would like to speak about five key themes that underpin the work that is being done by the New South Wales government in this area. These themes are the importance of a sustainable funding framework for disability services, the need for early intervention and transition planning, better day program and supported accommodation initiatives to support people as they age, the aged-care needs of people with a disability and the importance of building a sustainable workforce.

A sustainable funding framework is of vital importance in meeting the needs of people with a disability who are ageing. The New South Wales government believes that there is a need for all governments to work together to deliver a national system that is sustainable, cost effective, available for all who need it and can provide the specific services and supports that people with a disability and their carers need. The Productivity Commission inquiry into long-term care and support for people with a disability is an important milestone in the development of a consistent national approach to funding a sustainable disability service system.

The New South Wales government strongly supports the investigation of fair, equitable and sustainable options for a national approach to operating and financing services for people with a disability. It also strongly supports consideration of funding through a disability insurance scheme based on a social insurance model. It is also an opportunity to introduce a system that will provide the best possible outcomes for those members of the community who have a disability and for their family and carers.

Demand for disability services is increasing every year. People with a disability are experiencing a longer life span and this, together with the overall ageing of the population and the increasing workforce participation of female carers, is resulting in an increasing gap between the number of informal family carers who are able to care for a person with a disability and the numbers of people with a disability requiring care. This is leading to increased demand on formal care support services, particularly respite and supported accommodation.

There is a set of broader reforms underway under the National Health and Hospitals Network Agreement. Under that agreement, COAG recently agreed to changes to the roles and responsibilities of the Commonwealth and the states and territories in relation to the provision of aged and disability services. Under this agreement the Commonwealth will take full funding and program responsibility for the aged care system—that is everything from basic home care through to residential care. Responsibilities in relation to the Home and Community Care Program and the National Disability Agreement will alter with that Commonwealth responsibility being assumed. The split is at 65 years for people who are ageing and 50 for Indigenous persons. The states will assume responsibility for funding and service delivery for persons under the age of 65, or 50 for Indigenous persons.

The New South Wales and Australian governments will work in partnership to ensure seamless service delivery for people as they age, so that clients are not adversely affected by those changes in funding arrangements.

To maximise the potential of people with a disability to live as independently as possible and to participate fully in community life, early intervention is required to ensure that clients receive the most appropriate and timely support. ADHC recognises the need to provide a range of choices for people with a disability who are ageing, and their carers, at the earliest possible time. A number of strategies are being implemented across program areas that have a focus on early intervention and long-term planning strategies for this cohort of clients.

Case management services are being delivered under the support coordination program for ageing parent carers aged over 60 years—over 45 for Aboriginal carers. This program has a focus on engaging with older carers, identifying current and future support needs of the people with a disability for whom they are caring, and providing support for transition planning for the future.

We have 19 support coordination services across New South Wales. These important services are also linking families with appropriate services within the broader service system and are trying to build the independence of the person with a disability and helping them to transition from their current living arrangements to alternative options such as a form of accommodation support for the future, particularly when ageing carers are no longer able to continue in their caring role. In the future, ADHC has identified the need to connect with older younger carers—people younger than 60 years—and planning is underway to expand support to those of families so that we can get the support in at the earliest possible time.

Day program initiatives have also been developed to respond to the growing number of people with a disability who are living beyond middle age and transitioning into retirement. Central to this program is the recognition that a continuum of support needs to be provided to people as they age, including opportunities for futures and retirement planning. A number of supported accommodation models to meet the needs of people with a disability who are ageing have been developed.

A program initially piloted by the Down Syndrome Association is called independent living support. We have provided them with additional funding for this initiative to help them expand, so that they can look to support people with low to moderate support needs who have ageing carers, and you have the goal of community based living accommodation. The program aims to maintain or broaden long-term accommodation options in the community through intensive living skill development, development of support networks, and development of a plan to assist the person's goals and aspirations. We have also undertaken research in ageing in place. That responds to needs for an evidence based plan to better meet the needs of people who are ageing with a disability.

In addition, we have recently opened Casuarina Grove, which is a 24-hour, seven-day supported accommodation service for people with disabilities who are ageing. It is a 100-bed facility. It meets the aged care standards and it is configured in 10 homes of 10 beds each. Initially, this has taken a cohort of residents at the Peat Island centre who have age related support needs. They have moved in. That still leaves us approximately 40 places to fill, and we are commencing a process of finding the folks to match to those places. This model that we developed was based on a model in South Australia that is funded to also provide for that target group of people with an intellectual disability who have age related support needs.

In the fourth area, aged-care needs of people with a disability, to ensure that New South Wales is well placed to meet the challenges and opportunities that an ageing population presents, the New South Wales government has introduced a comprehensive whole-of-government strategy 'Towards 2030—planning for our changing population'. Towards 2030 responds to the challenges faced by the whole community as people age and includes a broad range of strategies for governments, business and the community to work together to plan long-term responses to population ageing. Through these strategies, older people will be supported to continue to participate fully in community life, including people with a disability who are ageing.

One key challenge facing people with a disability, particularly those with an intellectual disability, is the early onset of age related issues such as dementia. Towards 2030 responds through the inclusion of strategies to improve the provision of health and aged-care services for people as they age, including the management of chronic and complex health conditions. One such strategy is the New South Wales dementia services framework, developed by NSW Health, to provide a crucial guide for future dementia service planning and investment in New South Wales.

The last item I would like to speak to is the need for a sustainable workforce into the future. That is critical. As the rest of the population is ageing, we have a particular profile in our own directly employed workforce where the biggest proportion of our workers are over 45, with many of them over 55, and are themselves looking at retirement in the near future. To address that priority, the New South Wales government recognises that the disability sector must have a sustainable workforce and that strategies to strengthen the sector need to be implemented.

We have over the last five years had a funding initiative in disability in New South Wales called Stronger Together. That has put a significant injection of funds into the disability sector. As part of that strategy we recognised that we were not going to have a success with the increased funding if all we did was poach staff off each other rather than bring in new people to work in the disability area. So a lot of what we have done has been aimed at increasing the workforce, not just moving the employees. To do this, ADHC is working in partnership with the disability services sector to implement industry development strategies to build the capacity and sustainability of the disability services sector. Administered by National Disability Services New South Wales branch, the industry development fund aims to ensure that the workforce is skilled, capable and focused on people with disability.

To further strengthen the sector, an innovative workforce recruitment strategy has been established. The aims of the strategy are to raise the profile of the disability and community care sectors, increase the size of the workforce available and attract the right types of workers to deliver quality services. Carecareers is an internet based recruitment and multimedia advertising campaign that has been launched and is proving successful in attracting new entrants into the disability and community care workforces. An extension of the Carecareers strategy is called Project Able, a work experience and training scheme aimed at students in secondary school and university allied health programs, has also attracted much interest.

We have within the department also had an emphasis on attracting Aboriginal people to work in disability services and community care. This is part of our response to Closing the Gap. We have recruited 90 residential support workers to work in our group homes. We are recruiting another 90 this year. We have recruited 19 AINs, assistants in nursing, to be trained and to work in our large residential services, and we have piloted a program of recruiting home care workers for the Home Care Worker Service of New South Wales. That proved successful. We gave people a qualification in aged care and assisted them to get a drivers licence. We are rolling that program out across the state.

Senator BOYCE—For Indigenous workers?

Ms McAlpine—For Indigenous people wishing to work in the community care sector. The New South Wales government understands the importance of planning options and services for people with a disability as they are ageing. It also acknowledges the significant role that carers play in supporting people with a disability. We recognise the need to expand and develop future planning and support services for people with a disability who are ageing, including options for those who are being cared for outside of the family home.

Senator BOYCE—What is the age criteria for going to Casuarina Grove and the level of disability?

Ms McAlpine—It is aged related. We recognise that for some people with intellectual disabilities it is an age related condition but they might not chronologically be over 60 or 65. So it is by assessment.

Senator BOYCE—So it is an assessment that finds that you are demonstrating symptoms of ageing as well as having a disability?

Ms McAlpine—Yes, that is right.

Senator BOYCE—Would you be able to tell me the age of the youngest person in the home?

Ms McAlpine—I think it is in the vicinity of early fifties.

Senator BOYCE—What is the level of disability of people and the type of disability?

Ms McAlpine—They all have intellectual disability and many of them have multiple disabilities—of which one feature would be intellectual disability. There are people with sensory impairments, multiple disabilities and straight intellectual disability with very frail or unstable health conditions.

Senator BOYCE—I imagine you have had criticism of this as being re-institutionalisation?

Ms McAlpine—Yes.

Senator BOYCE—Would you like to talk about that?

Ms McAlpine—If you are 65 and you do not have an intellectual disability but your health needs warrant it, you would have that level of residential care if you needed it. The DSA actually says that you need services and supports similar to the regular community. We would be saying that this is something that the regular community can access. For people with disabilities not to be able to access something that meets their needs is actually discriminatory.

Senator BOYCE—In that this is for people with disabilities, how would it differ from a normal aged-care facility?

Ms McAlpine—Our staffing ratios are probably more generous. For example, many of the people who are currently residing there have difficulties in eating and drinking and require significant assistance to be able to eat and drink safely. So the intensity of staffing is different. The training of the staffing is different. They are all people with a background in disability services. They are people who are able to communicate with the clients who live there. There are high-quality interventions in terms of occupational therapy, day activities and diversionary activities for residents.

Senator BOYCE—I think you said that there are 40 people in there and you are anticipating getting that number to 100.

Ms McAlpine—We have over 50 in there. Do not quote me on the number but I think it is 52 to 57—or somewhere around there—and there are 40 more to come in.

Senator BOYCE—How will those people be chosen, selected, found?

Ms McAlpine—In the first instance we will look at within our current funded accommodation services to see if there are people there with age related needs that cannot be met in their current placement. They would then be considered and then people living generally in the community who require that level of service.

Senator BOYCE—Would you expect that you would find all the people—the 40 or whatever—currently living in supported accommodation?

Ms McAlpine—It is a bit hard to predict. I would think that we would find some of them but probably not all of them.

Senator BOYCE—So you would anticipate that some of the people going to this facility would be people who are currently living at home with older parents and carers?

Ms McAlpine—Yes, if we had the spots available and if that met their needs.

Senator BOYCE—I presume there has to be someone whose needs would be met by this. Is there availability is what I am asking?

Ms McAlpine—Yes, we have 1,700 people on our accommodation register. I make the assumption that in that 1,700 there will be people who would have their needs met by such a model.

Senator BOYCE—But those on the accommodation register do not include those who live at home with parents—is that correct?

Ms McAlpine—No, that is for people who are requesting supported accommodation, so they are with their family or other carers.

Senator BOYCE—And asking for supported accommodation. We have had evidence pretty much all day that says you have to have a crisis before you get any supported accommodation in New South Wales.

Ms McAlpine—Under Stronger Together we created 919 new accommodation places. We would state there is still a large demand as is evidenced by the fact there are still 1,700 people on that service register. Of those, approximately 1,000 of them have indicated an immediate need for something within the next three to six months. The other 700-odd are flagging a future need.

Senator BOYCE—What is a future need?

Ms McAlpine—Some of them are people with a teenage family member who are saying, ‘I would like this person to have somewhere to live in five to 10 years time.’

Senator BOYCE—What is the minimum amount of time that would be considered a future need so to speak?

Ms McAlpine—After a prolonged period of community consultation we have left that open.

Senator BOYCE—Okay.

CHAIR—Of the 1,000 that have indicated an immediate need, how long does it take to meet that? How long have some of those people been on the list?

Ms McAlpine—Quite some time. I do not have the numbers with me in the current system but we have 100 to 116 accommodation vacancies a year. This is our last year of Stronger Together part 1. The government is considering the requirements for Stronger Together part 2.

Senator BOYCE—Someone said earlier there is to be an announcement on Friday—is that correct?

Ms McAlpine—Yes.

Senator CAROL BROWN—With Casuarina Grove do you receive ACFI funding?

Ms McAlpine—No, it is entirely funded by the state.

CHAIR—And disability funding.

Senator BOYCE—Is that why it is all people with disabilities or if you could have a mix of aged people without disabilities and aged people with disabilities would you do it that way.

Ms McAlpine—At this time we are working on the assumption that we can fill the beds with people who have an intellectual disability and are ageing. At some point in the future that might change.

Senator BOYCE—Is Casuarina Grove a pilot project or are you anticipating putting one in in Newcastle, Wollongong et cetera?

Ms McAlpine—We have a number of nongovernment large residential centres which have also been undergoing business case planning that are being considered as part of Stronger Together 2 about what they wish to do with their remaining large residential centres. Many of those also have ageing populations in those centres. Some of them wish to turn those into aged care residential services for people with disabilities. We are not planning to build another directly provided one but some of those NGOs wish to undertake that redevelopment.

Senator BOYCE—To turn unused—

Ms McAlpine—They currently have a residential centre that might at some stage have had 50 people living there. They might now have 40 people living there who are all older people. They might wish to redevelop into 10 5-person group homes and focus on people with disabilities and aged care related needs.

CHAIR—Where would they get the funding from?

Ms McAlpine—That is being considered as part of Stronger Together.

CHAIR—The announcement that is being made on Friday may or may not contain funding for that sort of thing.

Ms McAlpine—I cannot comment on that.

CHAIR—We have been having extensive discussions about this boundary between aged care and disability and the fact that you age earlier when you have a disability. Have there been discussions with the federal government around those boundaries?

Ms McAlpine—It is my understanding that the states have not negotiated those boundaries yet with the Australian government. That is part of a process that needs to occur between now and when that split is formally made.

CHAIR—Current consultation is a bit of a thorn in my side at the moment because we are not getting consulted in WA around the aged-care reforms. I realise I am touching the boundary here between policy and opinion, but is that something that could be on the table during the discussions I understand are underway right now?

Ms McAlpine—I think that is policy.

CHAIR—Is it something that New South Wales thinks it is an important issue?

Ms McAlpine—I really do not think I can comment on that. There are a number—

Senator BOYCE—What can you tell us, though, about the level of complaints to you about gaps between federal and state funding?

Ms McAlpine—Part of the dilemma that we have had has been when we fund someone in, for example, a non-government group home. Their needs are assessed as they go in and a unit cost is agreed that is commensurate with the person’s needs. Over time those needs may change for a range of reasons—health reasons, ageing reasons or behavioural reasons. The process of coming back and renegotiating a change in funding or a top-up to meet those changed needs has for some NGOs been quite difficult. My department have dealt with that by having viability funding each year, where we would look at the case and see that the viability of a unit was not sustainable because of the change in needs. We would agree or disagree and negotiate some additional viability funding to assist the NGO to provide for that person.

CHAIR—Under disability funding?

Ms McAlpine—Under disability funding.

CHAIR—At the moment, if they come to you and say, ‘These issues are related to early ageing,’ is your response still, ‘We’ll deal with it as disability’?

Ms McAlpine—That is what we have been doing through the viability process. Sometimes that might be frustrating. It might be podiatry services that the person needs; we do not fund podiatry services. So there are some tensions around those boundaries for people.

Senator CAROL BROWN—We have heard also the concern that people have that, when a person with disability reaches the age of 65, they are now accessing aged-care packages, which are not as attractive as what they were getting under disability packages or do not meet their needs. They still have the same needs and, in fact, additional needs.

Ms McAlpine—If the person is living with us either in a facility that we operate directly or in a facility that we fund through an NGO, my understanding is that that would be negotiated at a high level between the state and the Commonwealth. It is our anticipation that the person would continue living where they are living and there would be an exchange at a high level; it would not come down to that person being told, ‘No, you have to leave.’

CHAIR—In Victoria we heard examples where the person had to negotiate that themselves.

Ms McAlpine—We would be hoping that that is not the case.

CHAIR—People in, say, Casuarina Grove under New South Wales disability funding as they approach 65 can, as I understand what you just said, stay there but their funding would switch over to Commonwealth funding.

Ms McAlpine—Yes.

CHAIR—Are there any people in there at the moment aged 65 or over?

Ms McAlpine—Yes.

CHAIR—They will be getting a portion of their funding—

Ms McAlpine—Right now it is all from us. When this becomes operational, which will not be for some time yet, that will be the case.

Senator BOYCE—So it is not open yet?

Ms McAlpine—No, I mean operational as in the Commonwealth-state split at the age of 65.

CHAIR—So you constructed that facility without applying for any of the ACARs knowing that people were over 65?

Ms McAlpine—We announced this in 2006, well before—

CHAIR—I understand that, but I would have thought you could have still applied for an ACAR knowing you had people aged going in there.

Ms McAlpine—I believe we thought we were ineligible and we saw it as a priority, so we did it.

Senator BOYCE—I want to just go back to the Life Choices program—and I think both the Life Choices and the Active Ageing programs have been mentioned by service organisations and by families today. The Life Choices program has an unemployment criteria—

Ms McAlpine—It has an unemployment criteria.

Senator BOYCE—and an age limit. Are you supposed to grow out of Life Choices and grow into Active Ageing; is that how it works?

Ms McAlpine—All of this is going to have some flexibility over time for people. These were both new initiatives that occurred through Stronger Together part 1.

Senator BOYCE—But they have been happening?

Ms McAlpine—Yes.

Senator BOYCE—We have had evidence today that they are not useful for people who are wanting to retire from ADEs, for instance.

Ms McAlpine—In terms of wanting something five days a week?

Senator BOYCE—Wanting activities to undertake in their retirement from work and that, because they do currently work, they are not eligible to cut back their work—

Ms McAlpine—I think the threshold is ‘not undertaking paid employment for more than eight hours per week’. So it is work a little bit but not work a lot. We know there is an issue of people in ADEs who are wishing to retire and there not being enough programs for them to move into. Then, of course, there is a problem at the other side because we fund a transition to work program and there is a blockage with people leaving transition to work and getting into ADEs. Clearly, we understand there is a need for more programs in those areas so that we can free up that cycle and make sure that those people who are capable of work get access to work and those people who would like to retire can retire.

Senator BOYCE—We have had evidence today suggesting that one of the current reasons why supported accommodation is crisis driven is the fact that all of the people who live in what were referred to as institutions, which are I presume what you call large residential centres, are having to be accommodated outside those centres.

Ms McAlpine—Everything we have done so far has been specifically funded for that. So in Stronger Together we increased 990 places in accommodation and at the same time Casuarina Grove came from what was Peat Island, a large residential centre—

Senator BOYCE—So that was refurbishment of an existing facility?

Ms McAlpine—No, it closed. We built two new entities and everybody moved. So for those people who were younger living at Peat Island who did not have age related needs we built four group homes on the Central Coast and they have transitioned there. There were some vacant places in that which we filled with people from the community requiring accommodation. Those with age-related needs moved to Casuarina Grove. That had been specifically funded as well as the 990 new accommodation places. That was also the case for the redevelopment of the Grosvenor Centre and the Lachlan Centre. Riverside was announced in the last budget as well.

Senator BOYCE—So there has been no effect on supported accommodation—

Ms McAlpine—We have done both. We have created new community supported accommodation places and also looked at the closure and redevelopment of those large residential centres.

CHAIR—How many of the 990 were people coming out of those centres that you were closing?

Ms McAlpine—The 990 were a range of people: 320 were general community available places, 200 were for people with an intellectual disability exiting the criminal justice or juvenile justice systems and a number were for people leaving care and had been wards of the state in the care of the minister and had disabilities. That was in addition to what we did with the redevelopment of the centres.

Senator BOYCE—Earlier you said you had 1,700 people on the waiting list for supported accommodation—

Ms McAlpine—Can I just clarify something. We refer to it as a service register. ‘Waiting list’ has the notion that you will make your way to the top. With the service register we deal with the people with the most extreme needs—

Senator BOYCE—I think that is also what Victoria calls it. We know that there will be an increasing number of people wanting supported accommodation. How many years is it going to take you to clear that register?

Ms McAlpine—I will take that question on notice. I would be guessing at the moment.

Senator BOYCE—We have also had evidence suggesting that, in the area of ageing, we have very good data and forecasting around the long-term needs going into the future. We have nothing like that in the disability sector. Could you comment on that?

Ms McAlpine—We clearly have some difficulties in that area, but that is not peculiar to this jurisdiction; it is every jurisdiction. The disability ministers are looking at a national project to try and address our capacity to model effectively into the future.

Senator BOYCE—Is that through COAG?

Ms McAlpine—I am not sure of the title. It is when the ministers meet with the Commonwealth—ministers responsible for disability in each state. For example, when we did the modelling work to get the funding for Stronger Together in the first round, we used 2003 ABS data on disability. We began doing the modelling this calendar year to inform the second round and there had been no new release of disability data. The funding put into Stronger Together in round 1 was $1.3 billion, but no updated data set could tell us the impact it had. We wrestle with being able to accurately model what is required into the future.

Senator BOYCE—From what you are saying, also to accurately evaluate in some ways the difference that your funding has made.

Ms McAlpine—We have done some work that has been able to show that. That was part of the Stronger Together 2 work that we did. But, yes, it is difficult. I would also say it is not a problem peculiar to this jurisdiction.

Senator BOYCE—No—I think it is a national issue.

CHAIR—I just flag that I suspect there will be questions on notice as well. We have had a number of organisations talking to us about various pilots. Today we counted four or five. What happens to them? There has been a number of them. What happens and why are they not re-funded?

Ms McAlpine—Clearly, some of those things informed the planning that we have done around Stronger Together 2. Some things that we did we thought were a really good idea and data has not demonstrated that.

Senator BOYCE—‘Have a look on Friday’—is that what you are telling us, Ms McAlpine?

CHAIR—We might make a list. I have forgotten all the different names. I should have written them all down. Maybe we could provide you with a list and, maybe after Friday, you could say, ‘This one was taken up. This one did not show us any improvement,’ et cetera. Would that be okay?

Ms McAlpine—Yes, absolutely.

Senator CAROL BROWN—There was some indication that people were not getting appropriate feedback as to what was going to happen after a pilot had finished and the evaluation report had been completed. Could you indicate—

Ms McAlpine—If you give it to me as a question on notice, I assume I can give you the answer after Friday.

CHAIR—Yes—certainly.

Senator BOYCE—Back to My Plan, My Choice: you note that 26 per cent of the families involved in that pilot are Aboriginal. We have not had a lot of evidence around families that care for a person with a disability in the Aboriginal community. Could you perhaps outline for us a little bit about this group and any other observations you have.

Ms McAlpine—Perhaps I could talk about one other thing we do. There is the Home Care Service of New South Wales and there is a subentity called Aboriginal Home Care. Aboriginal Home Care provides a lot of support to people with a disability who are living in their community.

Senator BOYCE—Is that for people with long-term disability or illness related disability? Does it make a distinction?

Ms McAlpine—Both. For some of them it is illness related due to health. For some it is disability that is longstanding and will continue. A lot of service is done through that model. There are a couple of reasons why it has been successful. The staff are Aboriginal, it is managed by Aboriginal managers and it is located physically close to Aboriginal communities. The feedback we get from that is that that is very important to people.

Senator BOYCE—Is it urban as well as rural?

Ms McAlpine—Yes. There are eight branches and it services across the state. As well as the branches, it has service outlets across the state, so it is in many quite small communities. Part of the difficulty that we have, for example, in my plan, my choice is that not all Aboriginal people wish to be serviced through general service provisions. Some do, and we have picked them up in my plan, my choice. Essentially, my plan, my choice is service packaging. It is an amount of

$50,000. The person indicates what they think they need to be able to continue living the life that they want, and that is funded within the $50,000. We are looking at a similar model, which would be managed by Aboriginal staff. We have just recruited for positions in the Illawarra, and it will start there. We are expecting the first staff members to come on just before Christmas. Again, that has got packages of about $50,000. It will be targeted at asking: ‘What is it that you need, on your terms?’, and they will try and broker that largely within the Aboriginal service provision.

Senator BOYCE—How many people will that assist?

Ms McAlpine—We have $5 million in the total initiative and they are $50,000 packages. We are starting in the Illawarra and then we will expand into Mount Druitt in Western Sydney and back up to northern New South Wales.

Senator BOYCE—Why have you picked the areas that you have picked?

Ms McAlpine—They have large populations of Aboriginal people, they are in areas that we believe are underserviced for Aboriginal people and there is strong local support for this model.

Senator BOYCE—Can we talk a little bit further about my plan, my choice.

Ms McAlpine—Clearly, this was our first go at packaging. There were two pilots: this one and another aimed at a different age group. They were aimed at packaging—how would we make it work, what were the guidelines, would we just give the money to the families or would be do something else with it? All of that has been worked through in those pilots. Our minister has a very clear desire to increase the availability of packaging in New South Wales, and it was part of what we looked at when we were doing the planning proposals that would be considered as part of Stronger Together 2.

Senator BOYCE—I have just one last question. The report *Futures planning for older carers of adults with disabilities* is exactly the focus of the inquiry. It was, again, a successful pilot project and you have expanded it. What are you doing now? How is that program working, how many people are being assisted and how?

CHAIR—That is more than one question!

Senator BOYCE—I will ask it on notice. I am particularly interested in who is actually undertaking the planning with them—whether it is a government worker or a not-for-profit organisation.

Ms McAlpine—No, they are all in the NGO sector.

CHAIR—Thank you very much. There will be questions on notice, so we have given you some homework.

Committee adjourned at 4.29 pm