COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

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

MONDAY, 29 NOVEMBER 2010

MELBOURNE

BY AUTHORITY OF THE SENATE

THIS TRANSCRIPT HAS BEEN PREPARED BY AN EXTERNAL PROVIDER

INTERNET

Hansard transcripts of public hearings are made available on the internet when authorised by the committee.

The internet address is:

http://www.aph.gov.au/hansard

To search the parliamentary database, go to:
http://parlinfo.aph.gov.au

SENATE COMMUNITY AFFAIRS

REFERENCES COMMITTEE

Monday, 29 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, Furner 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

HOBSON, Ms Leah, National Policy Officer, Australian Federation of Disability Organisations

CHAIR (Senator Siewert)—Today the Senate Community Affairs References Committee continues its public hearings for its inquiry into planning options for people ageing with a disability. I welcome a representative from the Australian Federation of Disability Organisations. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you, I understand, but I know that you have done this before. We have your submission, No. 48. I invite you to make an opening statement, and then we will ask you some questions.

Ms Hobson—Thank you. The Australian Federation of Disability Organisations is a national peak body seeking to move forward the rights of people with disability across Australia. We are an organisation made up of other organisations which are of and for people with disability.

For people with disability, the area of ageing is a major concern. People with disability who are older require specific supports and services and require those supports and services, most importantly, to meet their human rights needs. Under the United Nations Convention on the Rights of Persons with Disabilities, people with disability have the right to participate in the community through recreation, through leisure and through work. They have the right, most importantly, to be a part of a family. The Australian Federation of Disability Organisations is particularly concerned to ensure that any system supporting people with disability who are ageing meets those human rights needs by maintaining and respecting the diversity of people with disability and their needs both in terms of their disabilities—which may be wide-ranging and multiple—and in terms of their own personal situations.

People with disability come to ageing from a variety of circumstances. Some will have been in the disability care and support system for the entirety of their lives or for a large part of their lives. Some will have been living in family situations which will simply be at home and where they have not necessarily had access to a large range of supports. The reasons for those gaps can be as wide and diverse as the range of people with disability themselves. It might be that a person with disability has come from a rural or regional background. A person with disability and their family could be from a non-English-speaking background where the understanding of family supports is very different. Likewise, they might be from an Aboriginal or Torres Strait Islander background, where family structures and supports are also quite unique.

Some families who support people with disability have done so over a long period of time in an attempt to ensure that their child is not a victim of institutionalisation. This would be the case for many older parent carers. Some people with disability come to an ageing environment as a member of their own family. They may be a spouse and a parent themselves. They may be a sibling living with other siblings. Those sorts of individual circumstances need to be taken into account.

CHAIR—Thank you for that. We will go to Senator Boyce.

Senator BOYCE—Ms Hobson, you talked about the differing backgrounds that people have. Could you perhaps talk a little bit more about the issues for people in regional and rural Australia?

Ms Hobson—I would think that the largest concern for people in regional and rural Australia is that there is often limited access to support, if any at all, in terms of the formalised support system. So it may take people a long time to access support because there is none available. For instance, if you have an older person with disability whose family supports are disappearing, it may be that person has to be shifted to the first available facility in a formal support environment, rather than being shifted to a more appropriate facility, and that could be some distance away.

Senator BOYCE—So they lose their social networks, their familiar environment and everything?

Ms Hobson—Exactly. That is particularly important because part of the issue for people with disability is that local communities and local understanding and local acceptance are very important to their social inclusion. If perhaps you have a psychosocial disability, there is the local community understanding that there may be times when you behave differently. Similarly, for somebody with an intellectual disability or a severe physical disability, people understand that you communicate differently. If you are taken out of that environment, a whole lot of your social inclusion options are suddenly diminished.

Senator BOYCE—I am trying to put a real face to this. So this comes down to things like the local milk bar folk knowing what sort of milk you like to buy, so things like that?

Ms Hobson—Yes, it can come down to those sorts of things. It can come down to the fact that the local community has seen you and known you for a long period of time. So there are safety nets built into that as well.

Senator BOYCE—Unrecognised in many cases but nevertheless there.

Ms Hobson—Yes, exactly.

Senator BOYCE—A number of the submissions we have received have talked about the lack of knowledge that people have and also about the gaps that develop because of the split of the funding and responsibilities between Commonwealth and state organisations, particularly as you go from being a person with disability to an ageing person with disability. What is AFDO’s view on this?

Ms Hobson—We would certainly back up those submissions that are talking about the sheer lack of information within the system. People with disability and their families often find it very difficult to even know what is out there to be able to plan for their futures. In some instances there are some specific barriers for families from a non-English-speaking background. They have been in the disability support system. It takes 10 years to be eligible to get the disability support pension once you have arrived in Australia if you have disability. So that, combined with the additional language barriers and perhaps cultural perceptions around disability, might mean that those people have a much more limited access to information.

Senator BOYCE—As we have been talking to witnesses, I have been interested in the sort of life path of people with disability when compared to that of others, particularly in terms of the fact that people with disability often continue to live with their parents or family until the family no longer has the ability to care. Whereas, you would expect that in the general population children leave home some time between about 18 and 40 hopefully. Does AFDO have a view about this? Is there an ideal that we are missing? Should we be providing sufficient support for people with disability to do exactly what everyone else in the community does and leave home?

Ms Hobson—Certainly, it is our position that people should have every opportunity to participate in the community and to leave home wherever possible, and there are lots of barriers to that. People with disability may find themselves unable to find work, regardless of their ability to participate in the workforce. Some people with disability have very variable disabilities or very severe disability, and there simply is not a support system out there to give them the ability to live independently of family and informal supports. Sometimes people with disability, like some members of the community, simply choose to be closer to their families or to be more connected by staying at home. That would, we think, be a much smaller number than the current numbers of people with disability leaving home.

Senator BOYCE—Yes, because in many cases at the moment it is not about choosing to stay with your family, is it?

Ms Hobson—No, it is not all. But we do have to recognise that for some people that is a choice.

Senator BOYCE—Yes. What could we be doing to perhaps normalise that moving out of home situation for people with disabilities?

Ms Hobson—I think one of the critical issues, obviously, as I have just said, is employment—giving people with disability the financial independence to be able to plan for their own futures and to move out of home. Otherwise, they are reliant on perhaps the public housing system, which has very long waiting lists, and they are reliant on staying close to informal support systems, whereas if they are working there might be able to access other supports, like aids and equipment, that are more difficult to access if you are unemployed. So that is a big one.

I think it is also important for people with disability to have ongoing supports to live outside of home. That is in part about making sure that people with disability have appropriate access to universally designed housing, but it is also about making sure that people with disability who need, say, personal attendant carers have access to that support—and that that support is disconnected from housing itself. So we do not necessarily see that a person has to be clumped with other people with disability to live in the community.

Senator CAROL BROWN—Can I just ask a quick question?

Senator BOYCE—Yes, go on.

Senator CAROL BROWN—For those people who access employment services, can you tell us what happens after they retire from their jobs? Are the services that they need still there and the social connection that obviously they received through work? How has that been handled?

Ms Hobson—I think it can depend on a person’s situation. So again, if somebody is in a very small, close-knit community, they are going to have, paradoxically, more opportunity to participate and to remain connected to those social networks. But they may not have access to the sort of support they need to participate in recreation and leisure activities, particularly if they are a person with a disability who needs disability support and they are going into recreational activities that might be for older people, who are still, by and large, quite functional and have, as I would say, a temporarily younger body. So accessing the specific sorts of supports they might need in those environments could be very difficult.

For some people with disability, participating in recreation and leisure once they have retired is an economic exercise, and there are economic barriers to that. So people with disability more likely to be in lower earning brackets and in some cases they will have had higher costs throughout their life because of their disability. That means that, ultimately, they have not been able to save as much for their retirement and so they are not able to participate from that economic perspective.

Senator CAROL BROWN—In your view from what you have experienced, of people with disabilities who are entering retirement would a higher percentage be going onto income support?

Ms Hobson—Yes.

Senator CAROL BROWN—No you have any figures?

Ms Hobson—No, I can do some searching for you and see if there are any available, but not off the top of my head.

Senator BOYCE—In your submission you have spoken for some length about the need for employees—people working in the disability sector—to understand aging issues and for people in the aged care sector to understand disability issues. How would you see that being achieved?

Ms Hobson—I think that it is critical that training for staff done at the level of certificates in aged care or disability studies has some compulsory modules that cover these kinds of areas. I think that those formal training opportunities are very important and also that there is the opportunity for people with disabilities and for their families and supporters to be able to communicate with disability service providers about the aging needs of persons with disabilities or, vice versa, with aged care providers. So there needs to be some systems in place within those systems for people to feel like it is okay to raise these issues and open a dialog in more informal ways.

Senator BOYCE—You would not see that you might combine training to work in the aged sector or disability sector—that all the training could be happening in one place, perhaps with a major, for want of a better word, in one area or the other?

Ms Hobson—They would have some cross combination content in both sets of training.

Senator BOYCE—One of the submissions that we had today has suggested that a way to go would be to look at a disability wing on aged care homes—a wing for aging people with a disability in aged care homes—because there would not be the numbers to have homes specifically for older people with disabilities. What is AFDO's view on that?

Ms Hobson—Our view is that any segregation of people with disabilities is not ideal. In an aged care setting it should be possible for people with disabilities to achieve a fairly good rate of integration, given the right staff training and given that aged care facilities are required to be quite physically accessible in the first instance. We would be encouraging a more holistic model where people with disabilities are able to have a choice of which nursing home or aged care facility they go to so that they are not again placed in a position where, if a specific disability allocated bed is not available, they are on a long waiting list. Also, so that people with disabilities have the same basic right as everybody else in the community who is aging—to choose.

CHAIR—You and many of the submission make the point about aging in place. That is the same concept for people without a disability, which is to enable them to age in place. When you are making the transition into residential aged care, would you use the same approach that you are using for people without a disability who are aging—that is, it is up to that person to facilitate care at home through community care packages until somebody makes the decision that they want to go into an aged care facility. Is that the concept you are talking about when you refer to aging in place?

Ms Hobson—Yes, sure. We do believe that people with disabilities should have as much choice in the process as possible. People with disabilities, like others, should be given support to remain in their home environment or in a smaller home environment—say, shifting from a family home to a unit—in the community wherever possible if that is their wish. In particular the concern is to make sure that people with disabilities have access to the right information and support to make those decisions themselves. For some people with disabilities and their families accessing information is really difficult. Knowing what your choices are is a fundamental part of being able to make a choice. For a lot of people with disabilities the information that is provided might be at a higher language level or it might be in English which, if you have been speaking Auslan your entire life or if you use Makaton or another form of communication, is not necessarily appropriate. That is an important step and it is also important for people with disabilities to have access to independent advocates as part of that process as well. Often, as for people who are ageing without a disability, there can be some conflict at times within families about what should happen for that person.

CHAIR—Are people having difficulty accessing residential aged care? Are they being told that there aren't places available for somebody with a disability? Do you have any information on that?

Ms Hobson—I do not have any figures or anecdotal data. I can go away and find out if other organisations that we have connections with have some firm information.

CHAIR—That would be appreciated and obviously I will follow it up with the witnesses that we have over the period of the inquiry. Picking up on what Senator Boyce was saying about particular groups advocating for a specific wing or places, I was wondering whether there is an issue where people are finding it hard to access residential care.

Ms Hobson—I can go away and find out.

Senator BOYCE—I want to ask a ‘what does it look like’ type of question. We have talked about the fact that a lot of people with disabilities live with their families until the family cannot care for them because that is not always their choice but it is perceived to be the best option that is available to them. What do you see happening to assist that person with a disability to age in place when the parents cannot care for them any more?

Ms Hobson—I think the first step there is to be able to have a good planning process for transition as a person with a disability who has been living at home for their entire life may not have been exposed to the service systems. They may not have ever had to advocate for themselves or to find somebody else outside of their family who can advocate for them on their own behalf—

Senator BOYCE—Because the family has always done that, so to speak.

Ms Hobson—Yes, because the family has always done that and they might have done that really well. For people with disabilities, community participation might have been very much facilitated by their family. They would have gone on outings with their parents or with their siblings—whoever has been caring for them. They need to be given some gentle transitions over time to accessing appropriate supports in the first instance and then having some conversations with people about what they want to happen when their family is no longer able to care for them. Where appropriate it is about finding some ways for people to begin putting those things in place before they get to a crisis point of a parent dying or a family member simply not being able to care any further. We know that the disability support system is pretty much crisis oriented and, when you have something like a bereavement in your family, the last thing you then want to be doing is navigating a whole lot of other new systems as well.

Senator BOYCE—I am aware of people who not only lost the person they have lived with for 40 or 50 years but then have been moved to a community hundreds of miles from where they were, all in the space of a few months, because of the inability of the system to help them in any other way.

Ms Hobson—That would be similar to stories we have heard.

Senator BOYCE—Does the group that could do that assisting with the planning currently exist, in your view? How do we do that? Who helps with that planning?

Ms Hobson—I think the system is so fractured and so variable across Australia that to say that something like that exists—you might find pockets where a disability service provider or a local Home and Community Care service might be doing better at those sorts of things and in other areas but there really is no consistent planning across Australia or even across a jurisdiction that would allow people with disability and their families to access those kinds of gentle transitions. I know that some state and territory governments are starting to look at these issues and they are at various stages of doing so, some down the track of starting to make policy plans but some are only beginning to have conversations and some are not even at the point of conversation.

Senator CAROL BROWN—So the ability to enable people with disability to choose and to plan is all underpinned by your recommendation in your submission about an inclusion allowance. Is that how you would see it working?

Ms Hobson—That is certainly part of it. The idea that people with disability and their families should have access to some form of individual aid funding like a disability inclusion allowance is pretty critical to being able to plan because if you do not have the resources we were talking about with rural and regional and certainly Aboriginal and Torres Strait Islander people living in rural and remote communities as well, then you simply do not have anything to plan with. So it is important that the disability support system (a) is well funded and (b) is providing resources to people with disability and their families in appropriate ways that allow them to have the maximum amount of choice. But it is also about the other conversations we have been having today around making sure that the system is prepared to manage that too, so that you have a nexus of people or an agency that deals with this, that you have disability advocates and support staff in both the disability sector and the aged care sector prepared to deal with the changes that happen in people’s lives, and that people have access to adequate information so that once they have some form of individualised funding like a disability inclusion allowance they are then able to make appropriate choices.

Senator CAROL BROWN—In your submission you talked about the significant impacts raising the retirement age will have. Can you elaborate further for the committee on that?

Ms Hobson—Raising the retirement age will mean that people with disability are on disability support pensions for a bit longer, so they are perhaps locked out of some systems that might be more appropriate for them, particularly if they are acquiring multiple disabilities that are related to their ageing. So people with disability who have had a lifelong disability, for example an intellectual disability, may begin to have a vision impairment or a hearing impairment that is ageing related or they begin to experience dementia. If we are talking about raising the retirement age for pensions then we obviously at some stage are going to start looking at the retirement age for aged care systems as well. That means that people with disability who are acquiring multiple disabilities and who may need additional support earlier on will not necessarily have access to it.

Senator BOYCE—I have one last question, but there are many more I could ask if we have time. The aged care sector is one of the most highly regulated in Australia on the basis that we see people living in aged care facilities as a particularly vulnerable population. I would have thought that people with disabilities who are now aged are the most vulnerable of all. Has your organisation done any work at all on whether you believe that there is sufficient regulation in the industry—there are things like community visitor programs for aged care facilities—if there is to become an increasing population of people with disabilities living in aged care?

Ms Hobson—We have not done any work around this area, and it would certainly be interesting to see if there has been any work done. Off the top of my head I think that it is important to ensure that the regulations within the aged care sector take into account disability-specific needs. For instance, we did a consultation recently where we were talking to some people about the Productivity Commission inquiry. We spoke to somebody who had been in an aged care facility—a younger person—who had found that she could not access a hoist for independently going to the toilet because she was classified as being a lower-needs person and was in an ‘appropriate’ facility for somebody with lower support needs. It meant that there were no hoists in the facility, because the regulations did not deem it so. So it is important that disability support needs are taken into account when developing those regulations.

Senator CAROL BROWN—Have your consultations been with the Productivity Commission inquiry into disability care and support?

Ms Hobson—Yes.

Senator CAROL BROWN—Will you or have you made a submission to the Productivity Commission inquiry into aging.

Ms Hobson—We will be making a submission.

CHAIR—I want to come back to this issue about the age of retirement. It is an issue that has come up repeatedly, both in this inquiry and in others that we have done. The issue is the boundary between when you are on disability support and when you get the age pension. You are under the state system under disability and you are under the federal system on aged care. In many of the submissions—and you have raised it—there is the issue of aging with a disability. You can be aging earlier than aging without a disability. What are your recommendations? You have raised the issue several times in your submission. What would you suggest we do about it? There seems to be an artificial boundary there. One minute you are on DSP and next you are on the age pension.

Ms Hobson—Something does need to be done to ensure that there are not artificial boundaries. A part of that is ensuring that the training for staff is appropriate in both systems. But it is also about lowering some of those bureaucratic barriers between the two systems so that if you have a genuine need to be accessing the aged care system, because you are a person with a person with a disability who is aging—such as somebody who may have Down syndrome and then acquire some sort of dementia related condition as well—your needs can be assessed as genuine and you can access the support that you require regardless of your age. Conversely, if you have a disability and you need access to disability supports that are only for your disability, you should not have to go through the aged care system to get them if you are a younger person. That applies to people with disabilities who are young people in nursing homes and people with disabilities who are sometimes trying to access recreation or leisure and have to go through aged care assessment teams in order to get that support. So it is about resourcing both of the systems and making sure that some of the bureaucratic boundaries are more flexible.

CHAIR—Earlier, when we were talking about transition planning, it seemed to me that if we had some sort of life-long planning or better forms of planning we would necessarily need to do a transition. You would still need to do transition planning, obviously, for some people, but the emphasis would not need to be there as much if your needs were being met wherever you were in the system.

Ms Hobson—Exactly. That is particularly applicable to things like individualised funding, where a person does not necessarily have to be in one camp or another and there does not necessarily have to be an artificial cut-off age. So if you have somebody who has their own package, they are starting to experience ageing issues and they are under the age where they might officially be able to get support in more formalised support systems, they can still use that package to start meeting some of their needs that might be ageing-related.

Senator CAROL BROWN—That is all about the flexibility or the inflexibility in the system.

Ms Hobson—That is correct.

Senator BOYCE—I would like to explore that a little bit further. To me there would perhaps be some concerns around bringing aged care and disability sectors closer together in terms of community attitudes and the like, and whether we have sufficiently dealt with stigma, I guess, to not have people with disabilities suddenly lumped into what are, in fact, institutions—even if they are institutions of choice.

Ms Hobson—That is certainly a concern that we share. There is still this community sense, in some quarters, that it is okay to congregate people with disability in institutions.

Senator BOYCE—Because they are happy with their own kind!

Ms Hobson—Perhaps more commonly now you have this idea that people with disability are looked after and should be looked after. The autonomy of choice is taken away in that thought process about people with disability. So in addressing any issues about disability care and support, whether that be for people who are ageing or people with disability at any other stage of life, we need to address those stigmas. When you are talking about stigma for people with disability who are ageing it is a double whammy, because we have this idea that older people are not necessarily able to make their own choices or that they should just be shunted off into institutions—that it is appropriate for them to go into nursing homes.

CHAIR—I was just thinking that ageing therefore becomes the disability.

Senator BOYCE—Yes, that is one way of looking at it.

CHAIR—It just dawned on me that that is how some people may view it.

Senator BOYCE—Have you got any thoughts on safeguarding people against that sort of congregation stigmatisation?

Ms Hobson—As I said earlier, it is important that people with disability are supported to make their own decisions as much as possible. That means that they have access to information, independently; that they have access to advocates who can help them to promote their own choices and to fight for them if they have to; and that they have access to a system that is transparent in caring for them, both in terms of the disability support system and in terms of the aged care system. So if both systems are supporting a person with disability they are open to community scrutiny and government and funding-body scrutiny, and that the outcomes from those organisations for people with disability are measured in terms of the amount of choice that they give people with disability.

Senator BOYCE—You have mentioned individual advocates and individual advocacy a couple of times. As far as I am aware the funding in this area is not particularly wonderful at the present time. Would you see that more funding to support the current work of individual advocates would be the solution or are you talking about a new area of advocacy?

Ms Hobson—Supporting the current system is certainly necessary, and you are right in saying that it is not particularly well funded. It is important that individual advocates working in the broader disability sector have a good understanding of issues around ageing as well as issues around disabilities, but that is also another area where there might need to be some training for staff working as individual advocates. And of course the difficulty that you run into there is that it is the sector where there is not a lot of formalised training.

Senator BOYCE—No, and a lot of the people offering advocacy would not be paid staff, they would be volunteers supported by a paid staff person. Is that the case?

Ms Hobson—That is correct, so it is important that both paid and unpaid individual advocates have access to information and support that is necessary, and also that those people can access some specialist information where they require it so that the linkages between the disability advocacy and the aged care advocacy sectors need to be supported as well.

Senator BOYCE—Ms Hobson, in the past people have thought about lifelong planning or transition planning as doing a will and setting up a trust. Some of the thinking has gone past that. Could you highlight for us what you see as the most critical aspects of doing lifelong planning or transitioning?

Ms Hobson—First and foremost is choice for everybody concerned so that people with disability have choice, so their supporters and their families have choice. And that the system provides choice in transitions. For some people it may be that to access choice all they need is additional information. For some people it may be that they require some specialist services to help them transition from one system to another. Or that they may need gradual access to services so that they become used to even receiving supports that are more formalised. And for some people it will be a matter of financial planning and financial transition as well, and is important that those systems are appropriate too. So the continual establishment of special disability trusts that allow people to plan financially for ongoing support for people with disability is important, and it is important for governments at all levels to look at the fact that people with disability and their supporters and carers are often on very low incomes and unable to plan for big transition points that might require new equipment or transition to new accommodation, and those things cost money.

Senator CAROL BROWN—We were talking earlier about accessing the appropriate information for people to be able to make their choices. It has been suggested in some submissions that there be a one-stop shop, like a national information centre, where people can access appropriate information to make decisions about planning issues and providing other information about disability. What is your view on that?

Ms Hobson—I certainly think that is a very good idea, that having centralised information is very important, particularly because people may be moving within jurisdictions, and even from one local council area to another it can vary as to the sorts of supports you might be able to get, let alone state to state. I also think that when you are talking about access to information, it is important to remember that some access to information comes from peer support and comes from being able to meet people who are in a similar situation to yourself, so for people with disability to be able to meet others who are trying to navigate the support system and for families of people with disability to do likewise. Then you get access to information that might not be formally available. It might be that there is a service provider in your area which has a staff member who is really good at responding to one particular issue among people with disability, but you do not get to know that by calling a hotline, you get to know that by talking to people within your local community who have met that person and have had success with them.

It is important that the system supports those formal, centralised information access points and also peer support. It is also important that people are able to access information in lots of different ways. People from non-English-speaking backgrounds need to have access to interpreting services, as do people who use Auslan as their first language, and people with intellectual disability and their families need access to information in plain English. There are a variety of means that need to be considered when you are talking about having information centralised.

Senator CAROL BROWN—So the one-stop shop is an idea that you would support, but obviously your view is that the other services and other points of information gathering would need to support that.

Ms Hobson—Yes. It is not a case of one solution for the issue of information gathering.

CHAIR—We have run out of time. Thank you very much. We very much appreciate both your written submission and your evidence today. It is really helpful for us.

[9.45 am]

BIGBY, Professor Christine, Private capacity

CHAIR—I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you.

Prof. Bigby—Yes.

CHAIR—We have your submission and it has been numbered 7. I would like to invite you to make an opening statement and then we will ask you some questions.

Prof. Bigby—I speak from the position of being an academic who has been researching in this area since I did my master's in 1990. I have been looking at two sets of issues which I think often get muddled up. The first set of issues is around transition, planning, people who are living with their parents and what happens to them in middle age when their parents become incapacitated or unable to continue to care for them. That is the issue around transition and planning for the rest of somebody's life when they cannot be supported by their parents anymore. Then there is the other issue—which includes everybody, irrespective of where they have been living previously—which is ageing successfully for the rest of your life. This is something that is relatively new among people with disabilities, so there is not a lot of experience around how you do that.

There are two sets of issues, and I have done significant amounts of research in both—looking at planning and transitions for older carers and issues around case management programs and the types of issues that need to be considered when you are thinking about planning for the future and whether or not it is actually the responsibility of parents to do that or whether we need to take a different view.

The other set of research I have done is around retirement, ageing in place and the interface between health and age and care and disability systems. I think that one of the issues is that this is a unique group of people who are ageing with a lifelong disability. They have very different characteristics from a lot of older people, they are a very small minority potentially within the aged-care system, and at the moment there is a policy vacuum because nobody wants to take the responsibility for this group of people.

The issues around transition are inextricably linked to the lack of services and provision of accommodation. If there were sufficient disability supported accommodation available to people with disabilities when they chose to leave their parents' home—whether that be in young adulthood or in middle age—we would not have such a major problem. So the problem is created by the lack of accommodation within the system.

We have had a vision that people with intellectual disabilities in particular talk about that they should have a life like everybody else's, and yet we do not provide the necessary support to enable people to leave home and to live independent lives with the support that is necessary. So we have this block, this brick wall, that people hit when they do have to leave home when their parents cannot care for them anymore. It has created a problem which we could easily solve in the long run by providing more supported accommodation.

The focus has been very much on the families and carers planning. I think it is important that we have a broader perspective and think about people with intellectual disabilities, parents and families caring and planning together. Lots of the research suggests that people with intellectual disabilities are left out of the planning process and that what they want and what they expect are not necessarily factored in, and it is very hard to plan for the next 30 years of somebody's life if you are their parent.

The sense is, I think, that we need to think about what we are planning for, and I think it is useful to think about planning to care about a person and planning to care for a person. You can replace some of the roles that parents have done by planning to have other people to be involved in somebody's life—other people who care about them, who are committed to them, who are not part of the service system, who can act in an advocacy role, who can negotiate with services and who can negotiate flexibly for change as a person's situation changes. Where somebody lives and the type of support they get will change over time and cannot be locked in at one point in time, so planning has to be flexible, and the way to achieve that is to have people involved your life.

There are issues, too, around preparing for that separation, helping people to develop skills, to develop independence, so that they can easily separate from their parents while still maintaining, clearly, a relationship with them and other family members. The planning has to think about preparation for that separation as well as where somebody might live in the future.

There is an awful lot of research around retirement issues and ageing in place nowadays which shows very clearly that there are a lot of people in employment in supported employment services. Almost 50 per cent of that population is going to be aged over 50 in the next five or six years, and that is going to affect the viability of those business services. It is also going to affect the quality of life of those people who want to have less of a stressful life and may want to retire. At the moment, it is very hard to retire. People see it as an enormous risk because they may be left at home with no support to swap work for more meaningful activity of their choice.

The main issue in people ageing in place is for people who live in group homes. There are about 900 group homes in Victoria alone. There is a population in those group homes that is ageing. Ageing in place is much more complicated if you already live in a service system. It is not easy to make a service system flexible, and we have not paid a lot of attention to how to do that. Our research shows that there are a significant number of what I call ‘younger older people’ in residential aged care at the moment. These are not the younger people who significant attention has been paid to; these are people in their 50s, 60s and 70s who have an intellectual disability, who have ended up there because they have been unable to age in place in a group home or have gone there straight from the family home because there were no other options. Those people's health needs are met very well in residential aged care, but their social integration needs are not. They are isolated. They are a very unique group within those residential aged-care facilities. There are only two or three in each facility, and the staff have no idea about how to deal with them. Other residents do not like them being there particularly, and other residents' families do not like them there either, and we need to pay attention to that.

It is also very hard for people who have intellectual disabilities—who have, for example, Down syndrome and are ageing prematurely and have dementia—to get access to high-quality aged-care assessments, aged-care clinics and geriatric medicine. Because of the age barriers to those services, they are stuck at the interface. There are protocols that say you should not use aged care unless it is the last resort, so people get batted backwards and forwards between the disability system and the aged-care system. As a result, some people die prematurely. They do not get the type of treatment that they should have.

Those are just some of the issues. I do not want to carry on talking because a lot of what I can talk about is already written and published and it is in the public domain, so it is probably best to have a dialogue.

CHAIR—Thank you.

Senator BOYCE—I might just start where you finished, Professor Bigby. You have suggested that there are some people who may well die prematurely because of dementia that is not treated in either system. Could you just flesh that out a bit more for us, please.

Prof. Bigby—There are people who live at the moment in group homes. I would argue that the group home system, while it is not the best possible system, is a pretty good system. We know that you can get good quality-of-life outcomes in group homes. However, group homes are not set up in order to provide very intensive health care. Their staff are basically support staff whose aim is to help people be included in the community and to provide support for people to be engaged in activities of everyday life.

Senator BOYCE—And there would generally be no-one there during the day, basically, because everyone else is out doing something.

Prof. Bigby—That is right. They are about supporting people to live a life. However, they are people’s homes and they should be able to—and there is evidence that they can—adapt to people’s needs as they change. The problem is that there are not any mechanisms to support them to adapt. We have examples from some of our research where people have ended up in hospital. The hospital wants to discharge people; the group home say they have not got the capacity to take that person back. In one instance there was a threat. The hospital staff member said, ‘Well, we’re going to discharge them anyway,’ and the group home supervisor said, ‘If you do that, I’ll call the police.’ That is not a way to deal with the health issues of people with intellectual disabilities.

People are not getting the best chance of health care because there are no health advocates and there is very little understanding of health issues, particularly health and ageing issues, within the disability system. That can be easily fixed. It means that people whose needs change significantly end up being hospitalised and then, because they cannot go back, the obvious discharge place is into residential aged care.

Senator BOYCE—So how do we fix it?

Prof. Bigby—How do we fix it? We need to have a commitment, first of all, that people with intellectual disabilities who are in group homes can age in place and that we will put some mechanisms in place to enable that to happen, which means that we need to provide expertise around ageing and health issues into the group home system. You can do that either by having that within your system or by purchasing it from outside and bringing it in—partnerships between aged-care providers with that expertise and the disability system with that expertise. But we also need to have some systematic change through the hospital system, through the healthcare system and through the geriatric medicine system that recognises the unique needs of people with intellectual disabilities in those systems.

It is blatant discrimination against people with all sorts of disabilities that they do not receive high-quality healthcare services within the hospital system. There is a significant amount of research now that shows that their experiences are significantly dreadful. I am not sure that they are worse than those of some other marginalised groups, but they are not being responded to in the way that they should be. There is an expectation that, if you have a disability, you bring a carer with you who has to provide the care for you in hospital as well as the nursing staff. Why is that?

We should be having universal health services that are available and accessible to everybody. We need to have a flexible age limit for eligibility for aged-care assessment services, which are not only the gatekeepers to residential aged care; they provide comprehensive geriatric assessment for people who have age related illnesses. We need to be able to get that sort of quality assessment for people with intellectual disabilities to identify the whole range of health issues and do something about them.

Senator BOYCE—I do not know much about the treatment system for people with early-onset dementia. You may have answered the question, but are people with intellectual disability who are experiencing dementia getting worse treatment or less treatment than others with early-onset dementia?

Prof. Bigby—I cannot compare them to other people with early-onset dementia because we do not have that sort of data. What we do have is the experiences of people who have early-onset dementia with intellectual disabilities who are one of the largest groups of people who will have early-onset dementia because of the connection between Down syndrome and dementia. We have some research that I have been doing in collaboration with Jenny Torr, who is an old-age psychiatrist from the Centre for Developmental Disability Health Victoria. We have been looking at the pathways for people to get a diagnosis and then the pathways to care, and they are incredibly haphazard.

There was a recent literature review that said there were no pathways for this group of people. The disability overshadows everything else. People see them as a person with a disability first and cannot comprehend that they may actually need some good dementia care. We have a CDAMS system here, which is the first port of call for really good assessments about dementia and then case management and support for people with dementia. There was a recent review of that, I think it was in—

Senator BOYCE—What is CDAMS?

Prof. Bigby—CDAMS—something something memory service; I do not know what it is. They are clinics specifically to diagnose dementia and support people with dementia. They are part of the health system, but it is very clear from a review of those services that they do not have the expertise around people with intellectual disabilities and do not have the mandate either to provide support for those people because their age limit is much later; yet they are the people that together with some disability expertise could provide quality care. That is where everybody else goes for dementia care and that is where people with intellectual disabilities should be going to.

Senator BOYCE—I loved your distinction between people who care about and people who care for. How do we go about developing a system that gives people with a disability both—in two minutes, please?

Prof. Bigby—It is important that I primarily speak about people with intellectual disabilities and I think one of the problems is that we tend to talk about all people with disabilities as if they are all the same. They are an incredibly diverse group, so I will talk about people with intellectual disabilities.

Most people with intellectual disabilities get their primary support—the people that care about them are their family members: their parents, their sibling and their extended family. We need to make sure that we can support those people to continue to care about them into later life. It is very clear that parents are very good at handing over that sort of responsibility to their other children, and their other children are very pleased to take that because they have a lifelong relationship with the person with the disability, but not everybody has a resourceful family. We need to try and resource those siblings, the next generation, to understand about the disability system, to understand how to work the system for the best advantage but we also need to spend a lot of time earlier in people’s lives building their support networks, making sure that they have other people outside of their family, peers, other people without disabilities that are part of their network that can care and be committed to them.

We have talked about circles of support for years and years but we have not recognised how difficult it is to help people build and sustain circles of support if they do not already have them. There are some really good very small examples where that has been happening, but if you look at them carefully they are always very concerned, resourceful families. I worry about the generation of people that have come out of institutions—we have done a lot of work with people who have come out Kew—and about two-thirds of those people do not have resourceful, close families; they have nobody. You need to do the building throughout people’s lives but you need to recognise that many of this group of people do not have other people who care about them. The only people that know them—and not particularly well—are service providers, and that makes them incredibly vulnerable at all stages of their lives but even more in later life when they move out of the disability system if they get into the aged care system.

In terms of how you care for people, I am not sure we should be caring for people; I think we should be supporting people. I think the Productivity Commission inquiry is looking at a much more reasoned way of doing that, a much fairer way. People need to have a right to access the type of support that they need when they need it and a recognition for people with intellectual disabilities that they also need access to support with decision making. There are different sorts of decisions that people make in their lives, which will require different sorts of support. The idea of choice is very difficult when you have not had a lot of experience. I think we need to think carefully about what we mean by choice and how that can be supported and not just use the glib idea that everybody is informed enough to make choices and has the requisite experience of the types of choices they might make.

Senator BOYCE—I have certainly seen person centred planning where it simply means, 'We'll have a meeting and tell you what we're going to do, rather than just tell you what we're going to do.'

Prof. Bigby—It would be good to have somebody who is committed to that person who can say, 'Hang on a minute; how did you arrive at that; what are you using to say this person likes to ride in a bus for an hour a day?' You need to question a lot of the things that are assumed about people in those sorts of planning things. It is only outside people that can do that. We are never going to have sufficient resources to let everybody have a paid advocate who knows them well. What we need to invest in, I think, is building people's social networks throughout their lives so that, like the rest of us, they are connected to other people.

Senator BOYCE—Who does that? Is it funding to not-for-profits? Is it a government exercise? Who should do it? As you said, not all families have the resources to do it themselves.

Prof. Bigby—Who should do it? It is variable, like most things, but it certainly should not be the government. The government cannot build informal networks. It should be small community based organisations who can get to know people and get to know their local areas and the people that they come across. It needs to be done by people who are experts in that sort of network building.

Senator BOYCE—Do you know Street by Street in Victoria? It started out around Eltham, I think. It was simply a bartering system between neighbours, but it has come to be seen as something that you could do to support vulnerable or lonely people in the community.

Prof. Bigby—There is a lot of very interesting community development stuff that is going on. In Victoria a group of people connected with Annecto got some funding from the state government to try and build the networks of a group of people who are living with older carers. Their experience shows how difficult it is to do that, how long it takes and how sustained it has to be. There is the PIN group in WA.

Senator BOYCE—And Pave the Way and so forth.

Prof. Bigby—You are more familiar with the ones in Queensland. There are a lot of those small organisations. It is the smallness and the connection to the community that are important.

Senator BOYCE—What was the name of the Victorian one?

Prof. Bigby—It is a service called Annecto, which is a non-government organisation. It had a small program a couple of years ago—we did some evaluation of it—that was trying to support a group of people to develop their networks.

Senator BOYCE—Martin Laverty from Catholic Health Australia made the point that he would have thought there were two or three people with an intellectual disability in every aged-care facility that Catholic Health have. I am certainly aware of someone in Queensland who went into an aged-care home in her late 40s with her mother but is subsequently now eligible to be there, so to speak. In a way, it was the best solution. Now it is the best solution or the best option for her. But you mentioned that other residents did not want them there and their families did not want them in residential care. What are the problems there?

Prof. Bigby—We did a survey of residential aged-care facilities in Victoria a couple of years ago, which is published, and we have been doing some in-depth work following a group of people who were in group homes and watching at what point they transition into residential aged care and how that happens. What I talk about comes from those two pieces of research. The staff that we have interviewed talk about the fact that people with intellectual disabilities do not fit socially into those residential aged-care facilities because they are not seen by the other residents to be like them. They mention the fact that family members of other residents are not particularly happy with this group of people being there because they do not fit in, they are seen to be younger and they are seen as a threat to other people's status, in a sense—

Senator BOYCE—Status?

Prof. Bigby—Yes. People who are ageing do not necessarily see themselves as people with a disability, and this generation for quite a long time to come has not been brought up with the same values around people with disabilities as we have now. There is a sense that people with disabilities are children who should be cared for and really do not have a place with valued people. It goes back to the old normalisation, some of that stuff.

Senator CAROL BROWN—In your submission you talk about the need for people that are providing services to either provide disability services or aged care nursing services. There seems to be some inability to combine both. You either need nursing care or you need disability services. Is there any way the Commonwealth Disability Agreement can alleviate any of that need for service providers to pigeonhole somebody?

Prof. Bigby—I just remembered what the other point was. Also people with intellectual disabilities who go into residential aged care end up staying for much longer than anybody else. Everybody else tends to be in their 80s and 90s and they stay for about 2.7 years—

Senator BOYCE—Everybody else dies around them.

Prof. Bigby—That is right. They are staying for an average of 12 years and that is an uncompleted length of stay. So they have a very different trajectory. But to answer your question, there was an initiative under the dementia pilot pool program that was very well researched, very well funded, and there is a report that was written by the AIHW on that which I think I referenced in my submission. It showed clearly that it was possible for organisations that manage group homes to work together with organisations that do assessments and planning around health-related issues connected with ageing so that you can marry the two together, you can have partnerships, you can bring that expertise into the disability system and you can support people to have much better healthcare planning and allied health support and all those things. It takes a relatively small amount of money but you have to resource that partnership, otherwise it will not work. So there is a model there and it has been shown to work. The problem with that model is that they spend a long time trying to unpack who should fund this, what part of the extra funding is to do with disability and what part is to do with ageing. I think that is a waste of time trying to work that out—

Senator CAROL BROWN—Spending quite a long time on splitting the funds.

Prof. Bigby—Yes. The costing of that project showed very clearly that the top-up money was a fraction of what it would cost if you moved somebody into residential aged care.

Senator CAROL BROWN—We have had this issue raised many times about when you access Commonwealth funding and you also have to access state funding and where the barriers then go up, so it then turns out to be who is providing money and how much and not about the person.

Prof. Bigby—And there is this idea about double-dipping, that people with intellectual disability in group homes are double-dipping because they get money from disability services and for aged care services. The way to look at that is to say, well, you need to fund the disability system using the mechanism that recognises that people’s needs increase with age, and you expect them to buy in support and expertise or to develop their own expertise. That is another way to go, but you have to recognise that needs change and get higher as people age.

Senator CAROL BROWN—There is a bit going on at the moment with the two Productivity Commission reports, one into ageing and one into disability. We also have the National Hospital and Health Network reform in terms of the Commonwealth taking over ageing. What would you like to see come out of that? They are perhaps going off and doing their own thing and then not reconnecting.

Prof. Bigby—I think we have to have a coherent system that recognises that there are people with disabilities. People with disabilities have disability specific needs that last through their lives and that change, but they are also citizens and they need to have access to the mainstream services that every other citizen has access to. I would like to see a significant amount of resources going into making those mainstream services more accessible and more responsive to the whole range of people with disabilities and into recognising that particularly people with intellectual disabilities and other multiple complex disabilities aged prematurely. So using chronological age for eligibility into specialist aged services is not the best way to go. We have dealt with that for people from Indigenous backgrounds by labelling them as a special group who age earlier. We could solve a lot of these problems by doing that in relation to people with disabilities—classifying them in the legislation as a special group who age earlier and therefore should be able to access a whole range of aged care services at an earlier age. We need to provide resources into those mainstream services to be responsive. They are not going to do it on their own; they need expertise. That is one of the solutions.

Senator CAROL BROWN—You have done a lot of work about people with disability and early onset dementia. You have said it is easy to fix that, so in your view why has it not happened?

Prof. Bigby—I have struggled with this for a while. I think one of the reasons that it has not happened yet is obviously the Commonwealth-state split, but it is also a commitment to the rights of people with disabilities. When we have to fund them to a level that is necessary for a quality of life that is similar to the rest of the population there is this very economic argument. It is called the plasticity of care such that if you have a bed and somewhere to be then you are okay. It is seen that if you have a place in a group home or you have a place in residential aged care then you are more or less okay. All the issues about quality of life outcomes are ignored at a very basic economic level. It is not until people who understand about disability and who are committed to quality of life outcomes start to dig down and look at the disadvantaged quality of care that people have that they see why it is important and why the cost of supporting somebody with a disability as they are ageing is much higher for that group of people than it is for standard older people because you do not have all the informal support, you are already part of the system and you have much more complicated needs and things. At an economic level, and a very superficial level you can say, ‘These people are okay, they’ve got somewhere to be.’ It is not until you really understand the quality of life issues that you understand why it is so important to tackle some of these issues.

I think it has never been seen as a strong commitment from the people who make the decisions about funding, which is governments, because there are always, at the bottom line, economic arguments. The reality is that, when we look at the figures, the cost of somebody being supported in a group home is significantly higher than the cost of somebody being supported in residential aged care. It is in the interests, as you know, of the state government to push people into residential aged care and it is in the interests of the federal government to keep people in the disability system. Until we have sorted out that we have a strong commitment to quality of life outcomes, we are never going to be able to resolve some of those economic arguments.

CHAIR—Going back to this issue of state involvement and we are pushing that way more and more—states doing disability, Commonwealth doing aged care—that is going to perpetuate that issue that you have just been talking about in who is interested in pushing people where.

Prof. Bigby—Not necessarily, not if we also pay attention to the aged care system and work out how we can sort out that interface by identifying this group of people as a unique group who are going to need aged care services at an earlier age. Then we make sure that those services are accessible to them wherever they are living and that they are responsive to them and that means they have the expertise.

CHAIR—I am playing devil’s advocate here, I am a state government, I am keen to get that classification in the aged care system because from a pragmatic point of view the Commonwealth has to take responsibility earlier because we are saying, ‘These people come into the aged care system earlier.’ Why is it in the interests of the Commonwealth to agree?

Prof. Bigby—We are not talking about them coming into the aged-care system in terms of using residential aged care—

CHAIR—In terms of responsibility. What I mean is in terms of financial responsibility, if we are changing the classification so people need ageing with a disability earlier and they need to receive services earlier, is the Commonwealth going to resist that because they are seen to be then having to take financial responsibility?

Prof. Bigby—But in the long run it is cheaper for the Commonwealth, because if they can support people with some top-up money to stay in the disability system. It cannot be an either/or;

you are going to need access to both. You are not coming into the aged-care system holus-bolus; you are coming a little bit into the aged-care system. You are getting some top-up back into the disability system, which is cheaper for the Commonwealth than moving somebody completely into the aged-care system. That is the attraction of trying to sort out some of this.

CHAIR—I am sorry, I am just trying to tease out the argument. What we are saying is that that line between disability and aged care, we already know it is artificial, but we are moving more and more down the line of: that is how the financial arrangements are going to be. What we are saying is, ‘It just isn’t going to work.’ The system you are advocating is: you have a bit of both, so it is not a clear distinction between who takes responsibility—the state or federal government.

Senator BOYCE—There is a partnership.

Prof. Bigby—Yes, there is a partnership. There must be lots of other examples where there has to be partnerships between the two. The other way to think about it is that you do it on a fee-for-service basis—that there is disability funding recognition of age and the disability system purchases into the aged-care system when it is absolutely necessary. We are in to individualised packages. Those sorts of things, therefore, are relatively easy to do.

CHAIR—Yes, you would think so—sorry!

Senator BOYCE—I would suspect some of the outpatient hospital versus GP type cost-shifting that has gone on would demonstrate that it is not particularly easy for states and the Commonwealth to sort out.

Senator CAROL BROWN—We had evidence earlier—and I think you were here—and the recommendation that there should be some sort of inclusion package, an inclusion allowance, which is basically funding for the individual and their carers to decide on the support and services they need. You are talking about individualised packages as well—is that what you are talking about?

Prof. Bigby—I do not think so. One of the major groups I am talking about is people living in group homes. It is very hard to disaggregate those people’s individual needs.

Senator CAROL BROWN—That is what I mean.

Prof. Bigby—I am talking about recognising that somebody’s needs do change and therefore topping up the notion of support that you give them. Those people will never have individualised packages as long as they are living in that home type of setting. But the Productivity Commission, if it comes out in favour of a disability insurance system, will give that individualised notional funding to people, whether they actually manage to themselves or it is managed through services or a broker or whatever.

But I think we need to avoid what is happening in places like Ireland, for example, where there is an enormous fear within the disability system of moving people into the residential aged-care system because of the very much lower quality of that system. So what is happening is that they are building congregate care for older people within the disability system. We should not be going down that sort of track; people should have the right to stay out of institutions, to stay in as individualised as possible accommodation for as long as they are able to do that. We should be avoiding re-institutionalising people at any age at all, ever.

If you think about it, the aged-care system actually has a lot to learn from the disability system in terms of supporting people to be as independent as possible, in terms of rights, in terms of whole philosophy and orientation. We should not be trying to imitate the aged-care system in the disability system. But that is another issue.

Senator CAROL BROWN—Thank you.

Senator BOYCE—You have talked about the lack of shared responsibility between the disability sector and the aged-care sector, and the gaps that develop and that the CDA does not really address who is responsible and who is accountable. You mentioned some examples of overseas initiatives such as specialist geriatric assessment clinics et cetera. Could you give us some more detail on those sorts of initiatives that bring the two together?

Prof. Bigby—In the states they have what are called RRTCs, rehabilitation and research training centres, and centres of excellence. There is one in Chicago on development disability and ageing. That has sponsored a lot of development and training across both the disability sector and the aged-care sector about issues of people ageing with a disability. A number of the major universities in the States have research centres that run geriatric assessment clinics just for people with intellectual disabilities. It is a way of combining research with clinical practice. Those clinics pick up a huge amount of undiagnosed health issues and are able to act as the specialists to refer people and get them treated out in the community.

I have recently been in Ireland and there is a really good example there. One of the large disability services has funded a mobile dementia care service. The disability system has funded the dementia care service and has staffed it with people who are experts in dementia care—nurse practitioners—who provide a resource to their network of group homes to support people to be diagnosed and then to help them plan and adapt to the needs of the person as their dementia progresses. It is those sorts of models which are about resourcing and using aged-care expertise to help people age within place and get that access to good health care and things that we need.

There is a whole range of those sorts of examples that are relatively easy to find out about and that could be replicated here. There is not one answer here. Our system is different from other places. We need to do some demonstration programs and evaluate them and work out what works best. That project that was evaluated by the AIHW was a really good example of something that worked in our system. We probably do not need to look much further afield than going back to that work that has been done. We have spent a lot of time scoping the issues and doing pilot projects, and they have never moved on to anything more meaningful. I think we have to take the next step now and put some programmatic work into this.

Senator CAROL BROWN—In your submission under the implementation strategies, you talk about specialist wings in residential aged care. Can you explain to the committee what you mean by that.

Prof. Bigby—There is still the concern that you will hear people say, ‘Let’s build a specialist aged-care facility for people with disabilities.’ That has happened in South Australia and it is happening in New South Wales at the moment. There are a lot of people living in New South Wales institutions who are older, and specialist aged-care accommodation has been built for those people. They have just moved them from one institution to another. My argument is that if you provide specialist aged-care facilities for people with intellectual disabilities, you are continuing to segregate them. If you build beds, you will fill them up and you will have to fill them up with people whether they need them or not in order to get your funding. That has happened at Minda in South Australia, where there are people now in residential aged care who really should not be there but there were spare beds. If you build facilities, you will also then attract people from a wide area which means you will dislocate people from their local area and people will have to travel, because that will be seen as the only option for people. There are a lot of dangers in building specialist facilities. One of the solutions to avoid that and also to resource residential aged-care facilities to be responsive to people with intellectual disabilities is to have a bit of specialisation within existing facilities, so that you can skill up a number of staff so they learn the skills about interaction and that sort of thing.

Senator CAROL BROWN—You are suggesting that people skill up and that they are able to specialise. You are not suggesting that a wing be provided where just people with disabilities are located?

Prof. Bigby—No. I am suggesting we have some specialisation, and that is actually happening by default at the moment in Victoria. Word gets around that there are some aged-care facilities that are better than others and are good at dealing with people with intellectual disabilities. We have seen it happen in the course of this three-year study: the numbers in one particular place are increasing because it has got a good reputation. So that might happen anyway.

Senator BOYCE—A bit like mainstream schooling.

Prof. Bigby—That is right; you end up in the good places. The trouble with that is that there is often not extra resourcing into those good places and therefore they get overwhelmed, and for the people who are not in the know it is hard to find out about them.

Senator CAROL BROWN—Thank you.

CHAIR—We have run out of time. Thank you very much; both your written and your oral evidence are very much appreciated.

Proceedings suspended from 10.30 am to 10.49 am

COOPER, Ms Margaret, Member, Women with Disabilities Australia

CHAIR—Welcome. Ms Cooper, I understand that you have been given information on parliamentary privilege and the protection of witnesses and evidence. I invite you to make an opening statement.

Ms Cooper—I am here representing Women with Disabilities Australia. I have to apologise for my voice. My voice is actually part of the problem you are presented with. My voice stopped functioning four months ago for no apparent reason. I had polio in 1947, well before the vaccine, and I have used a wheelchair ever since. The people I represent today are those who went out into the community and had normal lives. I worked for 27 years. Many of my colleagues and friends became mothers, workers, teachers or whatever not only because we had a strong urge to go out and be part of the community but also because we did not have back-up services. I think our generation had to do things and the generation now has a softer life. But then they may have additional disabilities.

With polio and a spinal cord injury and various other physical disabilities, it was assumed that, once we got through our base rehabilitation that is how we would remain. But many of us have found now that there are new problems happening later on in the disability years—maybe 40 to 60 years post the initial impairment, which is quite different to ageing. There has been a lot of work done on this in America. People who went to rehab centres with me went out, walked around, climbed trams and did other things and then found in their late fifties they suddenly could not do it. They could not walk across an airport. I could not move my manual wheelchair any more. It was unexplained, unexpected deterioration physically.

We are going through that but at the same time we are being lumbered with issues concerning ageing—for example, arthritis. In my case, maybe it is my voice or maybe it is post polio. Nobody has been able to tell me what had happened when I woke up four months and was unable to speak clearly. It is very frustrating for me because I talk all the time—on the phone; everywhere. I am just glad that I did not take up a university tutoring position.

The group I come from are quite often well outside the disability framework. So what I would ask this committee to think about is helping these people manage ageing without having to come into a highly specialised network and so people can stay out of institutions—aged care, whatever. My group, which grew up without a lot of support could not wait to get outside of the special schools and the rehab centres and are very reluctant to re-engage with an aged-care system. I am finishing off a PhD and the group of people I researched had never consulted aged care, and some of them are in their eighties. Although they had problems, their idea was that they were not ageing; they were polio or spinal cord injury people. They did not identify with ageing. They do not want to go into ageing, because they see that as nursing homes and being told what to do.

The ABS and the Australian Institute of Health and Welfare statistics do not give a clear picture of how many of us are out there. You can look at the statistics in institutions but you cannot pick up us retiring workers, grandparents et cetera who are now moving into severe disability post the age of 50. The people I speak for are people with polio, cerebral palsy, spinal cord injury and neurological deficits like cerebellar ataxia et cetera. We age at a different base point physically to other people. It may seem obvious but in fact there has been quite a bit of American research into this. Because we have had a lifetime of using our bones and muscles unevenly we get more wear and tear than the average retiree. So we are starting at a reduced base point health wise.

We may have things like post-polio syndrome that we also have to face while we are moving into ageing. Women with disabilities are particularly vulnerable to osteoporosis, because no matter whether you are standing or walking, if you have got uneven muscle pull onto tendons and bones, you get osteoporosis. If you do not have even use, you get osteoporosis. So anyone who is in a wheelchair for any length of time, or wearing leg braces or back braces, is at risk. Do we know what to do about it? No.

American studies have shown that women with disabilities have additional problems with menopause. For some reason or other there is a much higher rate of surgical intervention rather than managing menopause in a less drastic fashion.

People with disabilities often start off with less financial resources to move into ageing. These are the people I know who did not get super until very late. They had less education, less employment and less chance to build up a resource base to cope with ageing.

We are very keen on ageing being seen as positive and that people are not seen as dependent on society. People say this to a stupid degree at times. We want to keep a reciprocal relationship between us and the rest of society, so we want to be seen as contributing as well as needing care.

The problems we have are, firstly, do we have post-spinal cord injury syndrome, or post-polio syndrome that has to be assessed and treated separately to ageing? The Americans say yes, the English say yes, the Australians say, ‘We don’t know.’ We need longitudinal research into following a group of people’s disabilities—it could include intellectual, sensory or whatever—to follow through to find out what changes need intervention and what changes do not. We want the national women’s health strategy particularly to look at women with disabilities in relation to what is happening here with sterilisation—surgical removal of the uterus—to avoid some of the menopause symptoms, where the surgery is being offered as a quick option instead of actually following through on a less drastic procedure.

At this stage we do not have any research going on. I was on HRT for 15 years, which is quite against medical guidelines. I did that because nobody knew any way of preventing osteoporosis until about five years ago. It was as effective as HRT. Now we find out, with American research, that HRT was not as effective as they thought. Maybe we should all be taking extra calcium at the age of 25 or 22. But there have got to be some guidelines. That would keep people out of disability systems and aged-care systems. We are talking about prevention.

People with disabilities have made their identities as workers, mothers, grandmothers, whatever. You do not want to go into a system that means you will lose your central identity. Often people have an identity as being proud of their disability, proud that they have got over whatever it was and achieved being a lawyer or some social role they have looked for. If there comes a time when we need assistance, we do not want to end up, like me, on five different programs with four different team leaders, all unrelated to each other. I have six organisations involved in my life, and each has its own administrative procedures. So how much of the money goes on me and how much goes on administration? You do not really want to think about that.

There needs to be a place where you can go for an assessment and say: ‘Is my problem cerebral palsy? Is my problem polio? Or is it that I’ve gone past the point of no return and I’m then into the young-old or the old-old and I therefore need to look at aged care assessment and geriatric medicine in my management?’ The only clinic that I am aware of in Australia that does anything like that, and it is very minimal, is Polio Services Victoria, which is funded under the state government ambulatory care and auspiced by St Vincent’s. They have a part-time doctor, a full-time physio and a part-time OT. You can go there for polio and you can get an idea about what your problem is. It is only an idea because they have no resources to carry out any intervention or any treatment, but at least it helps. That is for polio. Cerebral palsy? We don’t know. Porphyria? Don’t know. Ataxia? We don’t know. If you keep up your private health insurance, which is a hell of a burden, you can buy in consultations from various specialities, but there is no coordinating aspect and you have to be very assertive to go through that process.

We are hoping that in Medicare Locals there might be a point where you could provide some disability separate from geriatric medicine input. If you had those two components in a Medicare Local, there might be the point of starting some multidisciplinary discussion about how do we help these people stay in the community or move into some sort of care situation or another. And you would also have a locus for good information coming back to funders about whether programs are effective or not. Nobody dares challenge Polio Services Victoria because they are their only clinic in south-eastern Australia and there is very little follow-up from them. So who is going to say, ‘Are you effective?’ They were originally set up for 300 people. Because polio affected an unknown number—probably in the vicinity of 250,000—they started off with 300 clients and have moved to 1,900 in three years, and they are still funded for 300. So there are a large number of gaps.

Senator BOYCE—You have made the point that there is no Australian research on osteoporosis in women with long-term disabilities. You also make the point that hysterectomy rates for women with disabilities are significantly higher than for non-disabled women. You have mentioned the idea of cervical intervention in menopause being more common. Would you like to suggest what you think might be the reasons for this?

Ms Cooper—I really do not know. Researchers in America suggested—they could not actually say it because they would be sued—it was easier to get a surgical consult than follow through with long-term medical gynaecology support or intervention. They were not going to say that, but that is reading between the lines. And I would suggest that is the same here. Women with Disabilities has been working against sterilisation of young women for many years.

Senator BOYCE—That is another inquiry, I guess.

Ms Cooper—Yes. We do not know, we can only guess.

Senator BOYCE—However, whether the hysterectomies are done when the women are young or whether they are done at menopause would presumably be partly responsible for the increase in osteoporosis as well, wouldn’t it?

Ms Cooper—It is possible; we do not know.

Senator BOYCE—Just broadening that out, one of the suggestions that we have had in a number of submissions is the development of a centre of excellence on the topic of ageing and disability. Is that something that you would support?

Ms Cooper—I think that would be very good, provided you had the ability to go out to community health centres or Medicare locals and educate.

Senator BOYCE—Use the research, you mean.

Ms Cooper—Yes—go out and teach what you are doing. There is no reason why you could not use the centre of excellence and telemedicine, which they are doing at the children's hospital here and in aged care in Queensland. Why not have a videoconference with a patient at the centre of excellence and a remote consultant, or the other way around? That would be excellent.

Senator BOYCE—You also made the comment that there is insufficient information about the number of people ageing with long-term disabilities, and you have gone through some of the statistical evidence that is around. What do we need and why?

Ms Cooper—Over many years—more years than I care to remember—I have been involved with ABS steering committees and projects and things. There is a great reluctance to actually ask a question about disability in various surveys and censuses. There are all sorts of good reasons why, but I reckon we have better reasons to ask and to say, 'You have got to do it.' We are really working in the dark, and we are really working on the various surveys of Access Economics. They are about to do one on polio; they have done one on Parkinson's. I think they have done one on cerebral palsy; I am not sure.

Senator BOYCE—Are they national surveys or Victorian ones?

Ms Cooper—They are national, as are the surveys. It seems to me that ABS and AIHW should be able to get together and work out something that gives us some predictive value. All we go on are those clusters, those small surveys, and anecdotal evidence, and that is not good enough.

Senator BOYCE—Going back to talking about planning needs for people with disabilities as they age and their carers age, in the area of intellectual disability a lot of this is about trying to protect vulnerable people from exploitation or abuse when the family or the carers are not around. What are the planning issues for people such as you with polio or cerebral palsy et cetera?

Ms Cooper—We are the carers. I am looking after a 94-year-old father and a schizophrenic relative. I do not do hands-on care necessarily, except for rescuing Dad from going downstairs and things. All my colleagues are supporting people by guardianship or the administration of the public advocate or whatever. Does that answer your question or not?

Senator BOYCE—I suppose my question is more about what, if any, vulnerabilities do you see someone like yourself having when your family or whatever are not around?

Ms Cooper—The biggest issue, which has been happening for about four years now, is that we do not have carers in the workforce. We do not have enough carers. What is actually happening to me and other people who are as severely disabled as I am who are using personal care services to be able to remain in their own homes—we need people to come in to get us up, put us to bed and maybe do food preparation—is that the carers are not there. The National Disability Services are running various workforce studies, but on the ground, while we used to have students working with us as carers, they can now get more money waitressing or working in a supermarket or whatever. So we moved to the next level, which was foreign students, and as you know that is disappearing.

Over the past two years, for my team of nine people—seven of them have major psychiatric disorders—they are coming into the workforce and they do a good job, but they need much more supervision and much more training, and that is not being supplied by the service providers. So the people available to go into the workforce have changed. That is a significant problem for people like me who are living alone, where you have to give out your door key. They can have access to your computer. There is no-one to answer an emergency call if you ring. One of my friends was actually threatened by a carer with a knife—this was two years ago. She was a trained nurse and she talked the woman down and said: ‘All right. I’m not going to have a shower tonight. You don’t have to put me to bed; I’ll get a friend to do it.’ She rang the agency the next day and said, ‘I don’t want that woman back.’ The agency said to her, and it is a very well known agency: ‘I’m sorry; we’ve got no-one else to send you.’ So those issues are really dominant in our minds. I insist on knowing who is coming into my place, but even that—

Senator BOYCE—That does not seem an unreasonable thing to insist on.

Ms Cooper—No. I have talked to some of the NDS people about it informally, and they say there is no money for training, there is no money for supervision and there is an increasing demand for personal care workers to come into the field. There is an increasing demand, under various welfare reforms, for people to go into the workforce. That is fine. That is good. That is excellent. But you have got to support them. A worker has to be able to ring up the agency and say, ‘Look, I really can’t stand Margaret; I can’t work with her,’ and be able to be taken off my case and put on someone else’s. There is no mechanism in any agency that I have used workers from to deal with that. So the workforce really is an issue—and it is disappearing and it is ageing. We have to get smarter with assistive technology perhaps.

Senator BOYCE—Yes. Another area that you talk about is people with disabilities becoming homeless because they do not own their own home. This is basically around the fact that there are huge waiting lists for public housing and for any other form of accommodation for people with disabilities.

Ms Cooper—Yes, that is a big issue in Victoria.

Senator BOYCE—Are you aware of people who have become homeless because of this?

Ms Cooper—Yes.

Senator BOYCE—How do you live on the streets with a disability?

Ms Cooper—Well, you have only got to walk down our mall and you will see them. It is a real problem. I live in Chelsea, which used to be an area with low rents. Rent has now moved up from $150 a week, roughly, to $300 a week because it has become more fashionable to go down to Chelsea and get on the nice, clean beach on the way to Portsea. Mostly, the people I know who are out there are people with psychiatric disabilities or sensory disabilities, particularly deafness. People can recognise blind people; they do not recognise deaf people or people with psychiatric disturbances, except to say they are a bit of a nuisance. I have been to real estate agents with a deaf friend of mine—could not get a rental. For the last place I got this person into, I had to give them a copy of the title of my property to say, ‘I am able to guarantee this person’s rental.’ She pays it herself. But she is going to be out of the market next year because her rent is going up from $185 to $250 a week. You cannot do it on a pension.

My relative with severe schizophrenia was homeless for three years, partly because she was right off her head. When she settled down there was no place for her to go. She is 54 and now living in aged care in a supported residential place, which I believe is going to be talked about later. She is recovering and able to participate in the community, but she has no stimulation in aged care so it is a really big problem. The people with psychiatric impairment whom I see coming to my place are all living on the edge—maybe doing rental. I do not know how we get around that except by increasing public housing. But if you increase public housing you have to get money from somewhere, don’t you? It is really a big problem. I think community housing, supported housing schemes are the only way to go—where an agency manages a certain number of properties.

Senator CAROL BROWN—In your submission you talk about the great distress that is caused by the arbitrary cut-off of disability services at age 65 with the transfer to aged care. Can you elaborate on that for us.

Ms Cooper—I understand there is some change, anticipating 2011. I am now 67 and next year I will be officially aged. Talking to my three case managers and four team leaders, I said, ‘What’s this going to mean for me?’ The answer: I do not know. ‘Am I going to be transferred to aged care and, if so, what happens to the disability part of me?’ I see myself as disabled and getting older, but a lot of my friends just see themselves as disabled. We do not know what is going to happen. There is a lot of worry out there; we just do not know.

CHAIR—One of the many concerns is with regard to the assistance you receive under disability support. It is unclear as to whether that is going to continue when you transfer to the age pension.

Ms Cooper—That is right—and who is going to fund it? I had a preliminary battle with this. I am not the only one, I have to stress. I had a preliminary battle with this last year. I do hydrotherapy once a week to keep me flexible. As soon as I turned 66, the agency that funds that care said, ‘Right, you are now in aged care; we are changing your service provider,’ and they changed me to a provider that had very little experience with disability. Being able to talk better last year than this year, I yelled and carried on and asserted myself and finally got my hydrotherapy transferred back to a provider with disability experience. If I had not done that I would have been in aged care, teaching them how to look after me. I do not think that is appropriate. That was a preliminary battle, and that case manager from that agency said, ‘Margaret, get ready for 2011.’ Great.

CHAIR—On 2011, is that because that is when the differences between aged care and disability packages will kick in?

Ms Cooper—Yes.

CHAIR—Or because of your age?

Ms Cooper—There is this funding—sorry, it is both.

CHAIR—You are caught right in the middle, in fact, because you are at that age but also because that is when the system is changing.

Ms Cooper—Yes, I have actually reached that age but they are a bit scared of me.

CHAIR—I find that hard to believe.

Ms Cooper—Could I mention one other thing that I think might be helpful for people—that is, in the Polio Network that I belong to we decided we had to educate our members as to how to handle post-polio syndrome and how to handle ageing—whatever they like to call it—to recognise the differences. We produced a self-help program they could take to their doctors, acupuncturists or whatever. There is no reason why the diagnoses could not do that. I said in my submission under (5) that we should look at the English Expert Patients Programme.

CHAIR—I was going to ask you about that.

Ms Cooper—I know how to manage me but I do need help in diagnosis. I know I am getting weaker and I know why, but I do not know why my voice failed. According to Yankee research it happens to about one in 150,000. I did not know that, but now I do. It does not help, but at least I know there is a reason and it is not psychiatric.

All our doctors in polio have died. I will probably talk to you about cerebral palsy later on, but a lot of the original doctors have died. The therapists have retired or died. We moved out of the system because we could not stand it. Now we have to come back in for expert advice. We know ourselves, so we think it could be something along the lines of the diabetic program, maybe, where we could be asked: ‘What do you think your problems are? How do you think they could be managed?’ and some way that we could go over the terrible sensitivity of doctors who really do not like the patient knowing as much as they do. It is a terrible problem they have got; they do not like to listen. If we could work in a consultative way and say, ‘All right’, I think that could be done for all sorts of disabilities and keep us, again, out of the very specialised programs.

Senator BOYCE—What does the British expert patient program actually do?

Ms Cooper—I am getting back to my thesis now. I could send it to you. With the group I am thinking of it happened in America, in Scotland and in England. They took a group of people with arthritis and said, ‘This is what your disease is. This is what is happening to you. How do you manage it?’ and then they said, ‘These are our suggestions for managing your condition so you do not deteriorate so quickly, and you may even get some benefit from it.’ They found in the three programs I read about that there was improvement in the people’s own perception of themselves and some measurable improvement in their condition. It was more about the people’s ability to handle themselves and continue being mothers, fathers, grandparents et cetera. The problem they had, particularly in England, was that the doctors resented it bitterly—absolutely bitterly.

CHAIR—The patients were not classed as experts.

Ms Cooper—No. It is the grey suit syndrome, isn’t it? We have got the makings of it in Australia. There was some money put over I think about four years ago to set up that sort of program. I have not got my notes here; I will have to send it to you. It was not called ‘expert patient’.

Senator JOYCE—Was it Commonwealth or state money?

Ms Cooper—Commonwealth. A lot of it went into the AMA funded research, which you would expect. But if you like I can send you those references. It was only in 2004. The AMA did bring out a supplement on it in the Medical Journal of Australia saying, ‘It is possible, fellas.’ One of the reasons I choose female doctors is that I have found that they have had to compromise all their lives and work out priorities. They understand where I am coming from and they seem more ready to accept that the patient might have an idea about self-management. I do not know whether a difference between female practitioners and male medical practitioners is going to show up here, but I think that is one way of helping to keep us out of the really underfunded specialist intervention programs.

Senator CAROL BROWN—I am going to ask you about your comments about portability services across the state. We have got issues just with going from one income support to another. You mention it in your submission. Do you want to elaborate on that?

Ms Cooper—It is probably more in the area of the Australian Federation of Disability Organisations, but women have reported to WIDA that they cannot move interstate because they have to then go on the waiting list for personal care or whatever program they want to get into. They have to go back on the waiting list so if their husband moves work they cannot move.

Senator CAROL BROWN—Obviously that would be an issue that you would put forward, in terms of planning options for people with disabilities, for the government to assist with.

Ms Cooper—Yes, but I do not think it is as much of a priority—I will get lynched for this!—as doing some longitudinal research and prevention of health problems, such as osteoporosis, because that happens to men as well, particularly men in wheelchairs. It is not just a women’s problem; it is just that we scream louder for intervention than they do. So I am prioritising—and we should not be prioritising; that is your job—but I really think prevention and other steps are more important at this stage. But it does reduce the quality of life for people who want to move interstate for work.

Senator CAROL BROWN—Your priority is the research that you have been talking about. Do you have any other priorities?

Ms Cooper—The priority for me now, like Chris was talking about before, is to look at whether we need some sort of centre of study, research and excellence. I think we do. The next question is whether it should be funded to work with Medicare locals so that we are getting the health information assessment out into the community, rather than bringing everyone in as a ‘client’, where you get waiting lists and all sorts of things happening. I think right now we are in the stage of people having problems functioning. We need to look at that and at what steps we can put in now to keep people healthier and in the community. And that goes along with public housing.

Senator CAROL BROWN—Thank you.

CHAIR—I want to go back to the issue you raise at the beginning about women with a disability living in poverty and being least prepared for retirement. This seems to me to be part of women in general being least prepared for retirement, but women with a disability are even less prepared.

Ms Cooper—Yes, because often they have not had the chance—we are talking about my age group now—to have got a good education and good employment.

CHAIR—And super kicked in late, even if they were able to get into employment later.

Ms Cooper—Yes.

CHAIR—You make comments in the submission in relation to ageing in place. We have been talking about issues for people who are ageing even if they have managed to move out of home and be more independent, but there are also issues for people who are still living with their parents who are ageing. What specific issues do you think we should be tackling in making recommendations to help that specific group of women who are worse off financially than virtually any other group? If we are going to help people age in place, what specific issues do we need to make recommendations about to deal with that?

Ms Cooper—We need community based care, and not just for people in wheelchairs but for people with psychiatric impairment. We really do need that on the ground. If I move my relative into the community in a flat, which is what she is always asking me for, there is no-one there to help her. There may be home help once a week who are not trained in managing people with schizophrenia, and she has a severe degree of schizophrenia. I understand that some organisations like the idea of cluster housing. I am not against that, I do not think WIDA is against that, so long as it does not get to the point of more than, say, 20 individuals in one place.

We are not talking about hostels. Cluster housing means, to me, independent living units with a central service system. I think that is a possibility that would have some economy of scale for running services. I see with psychiatric impairment and deafness—particularly deafness—terrible isolation when a person is in a flat in a block and get visited by a home-help person maybe once a fortnight and otherwise are in a world by themselves. So I think cluster housing would be possible.

There are some models in New South Wales and I believe MS Society and Australian Home Care are running a small cluster housing group in Melbourne for people with severe MS who want to live independently but do not want to move into a nursing home. It is a sort of compromise. I think that it is possible and I think it could be run by community housing organisations. That would modify the housing problem to an extent and you would also have services available when needed or when directed. Sometimes people have to have services even if they do not want them.

For me, no way—I do not want to go to a nursing home. I can see that that is a possibility if the workforce dwindles further but I would not be against small cluster housing if that is going to be the only way I can manage in an independent situation. There has to be some new thinking.

CHAIR—I have had very strong advocates against cluster housing in the. It is one of those issues that—

Ms Cooper—I think you have to ask people with disabilities. It is almost automatic cant from various sectors of the disability provider network, ‘No, you can’t have cluster housing.’ But if you talk to people with disabilities you find that often they would like to have more active neighbours. You are not going to get that from the people who are working two jobs to pay a mortgage. You cannot get it. You do not get neighbourhoods like that any more. But if you can get it from other people in a similar situation in a small set up—maybe 20 is too much; maybe 10 is better—I cannot see why people with disabilities would not select that as an option to live in, isolated and without service. I think people are not listening to the people with disabilities. They are listening to the providers. But the rhetoric was really good back in 1981, the Year of Disabled Persons, when we closed down all the institutions and moved them out, but that is not facing the reality we are in now. It is a different society now.

CHAIR—Thank you. We have run out of time. Thank you very much. I think we have given you some homework in terms of some references.

Ms Cooper—Yes.

CHAIR—That would be very much appreciated.

[11.34 am]

BAKER, Ms Lesley Joy, Parent Representative, Carers Victoria

COLLIN, Ms Emma, Executive Manager, Marketing, Strategy and Policy, Education and Research, Carers Victoria

PIERCE, Ms Gill, Program Manager, Policy and Research, Carers Victoria

CHAIR—Welcome. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. We have your submission, No. 54. I would like to invite each of you or one of you to make an opening statement, and then we will ask you some questions.

Ms Collin—Thank you for the opportunity for Carers Victoria to present to the committee on such important matters. Carers Victoria is a state-wide peak organisation representing over 700,000 carers and is a member of the national network of carers associations. Carers Victoria is a non-profit association with about 5½ thousand members, but we engage with and provide direct support to over 20,000 carers annually through our information, support, counselling and education services and through direct carer engagement on key issues.

Future planning is a key issue for ageing people with a disability and their caring families. It is a key issue for many parents, regardless of their age, particularly when their son or daughter has an intellectual or psychiatric disability or a decision-making disability. Carers Victoria has worked systematically over many years to draw attention to the needs of ageing parents and to promote the need to support families of people with disabilities with planning for the future. This has included analysis and research of practice literature, development of several submissions concerning the needs of ageing parents for FaHCSIA on behalf of the network of carer associations, analysis of the special disability trust mechanism, submission of proposals for reform to FaHCSIA and to the Senate inquiry, participation in the Victorian Law Reform Commission’s review of the Guardianship and Administration Act.

Our explicit purpose was to advocate for mechanisms for the advance family appointment of guardians or administrators to oversee the affairs of people with a disability. The participation involved consultations with 35 caring families about their experiences of the current system. We have also done work with the state disability services administration to advocate for and develop a program of support for ageing parents, consulted with over 200 families about their housing and support needs and future plans, developed an older parents support program and an older parents support group in the western metropolitan region in which 60 families are involved, and developed and trialled a five-part education program for ageing parents and their families about future planning. We are also supporting other programs and the development of future planning workshops. Our presentation today will address terms of reference (a), (c) and (d)—that is, the inadequacies in choice and funding of available planning options, the types of options and services that could help people with a disability and their families to plan for the future, and some other matters. I will hand over to Gill.

Ms Pierce—As the committee will no doubt be aware, it is really hard to think about planning options for older people with a disability and their families separately from considering the needs for housing and support. We know that is not really part of the terms of reference, but the two are intimately linked. Lesley’s presentation will give a clear outline of the importance of older people having access to resources to assist them to plan and implement housing support arrangements for their offspring—arrangements that can be phased in and supported while the parents are still in a position to do so.

For this hearing we are focusing broadly on disability as inclusive of people with physical, intellectual and psychiatric disabilities who also have a decision-making disability. They are the people who are less likely to be able to plan for their own futures and more likely to have limited access. They are the people whom families have often supported and assisted for a lifetime, and they and their families are anxious about what will happen in the future, as I am sure you know.

Our observations are that there are many inadequacies in the choice and funding of planning options for people with a disability and their families. In Victoria there are many legal and other barriers to planning. For example, there is no access for people with a disability or their families to mechanisms which would allow them to appoint substitute or supported decision-makers to make anticipatory appointments of enduring attorneys or enduring guardians. Parents cannot make such anticipatory appointments on behalf of or in consultation with their sons or daughters. Most families, not necessarily just parents, would prefer a trusted family member or friend to take an ongoing representation role with a person with a disability.

In Victoria the Civil and Administrative Appeals Tribunal has a protective rather than an enabling focus. It deals with crises in people having representation and support rather than in prevention. Its orders are usually things of the last resort and they are short term and often related to a single decision. In Victoria the system relies on informal arrangements, and that is not necessarily a bad thing, through the person responsible mechanism, part of the guardianship and administration system. While that works well for health decisions, it is not a suitable arrangement for helping people with a disability with their legal and financial matters.

We think that a mechanism for formal succession, what we call succession arrangement, can be an enabler for planning discussions within family and friendship networks for the future. It can compensate for limited access to housing and support, it can ensure that significant people in the life of a person with a disability can have ongoing responsibility to support and assist them, and it can be an important mechanism for families whose sons and daughters no longer live in the family home. Often old parents and younger parents continue to provide advice, guidance, encouragement and financial support to their son or daughter living outside of the family home and they too are anxious about what is going to happen when they can no longer do so.

Currently mechanisms for support or substitute decision-making are not available for people with a decision-making disability because they have never had what is known as capacity. But most of those people, in our view, have views concerning who could take an ongoing role in assisting them, who they would want to do that.

Other issues are inadequacies in services in Victoria and inflexibilities and limitations of special disability trusts which are complex and invisible to many families. I am sure the committee knows all about those from your own work.

CHAIR—We are having an inquiry into it.

Ms Pierce—We had much to say to that. But families have poor knowledge that this is an option. In some of our recent consultations with families about other things we have become aware of a number of low-income families who purchase housing for their son or daughter and then find that that purchase has affected through the assets test their own pension payment and they had no idea that that would be the case. That is really sad.

There is poor access for older people and older people with a disability to get assistance with what are essentially complex and multifaceted tasks in planning for the future. I think the advice families get is piecemeal rather than comprehensive and the planning tasks involved require a whole lot of knowledge and expertise. For example, to have access to discussion about housing and support options and models in collaboration with the person with a disability and other significant people, you need to know about financial planning for the future. You need to know about rules in estate planning, about distributing your property and your assets and how you might record future wishes within those. You need an understanding of formal guardianship and financial administration, what they offer, what the weaknesses are. You need to know about the pros and cons of various forms of trust arrangements for your son or daughter. You need an understanding of the operation and implications of Centrelink’s income and assets test and gifting rule. You need the opportunity for family discussion about roles in succession plans, family plans, support networks in the future for the person with a disability and you need to develop and share with significant others emergency care plans, what happens when you are ill; when you are carted off to hospital, how the carer of your son or daughter can be maintained.

Our understanding is that a whole lot of non-government agencies play a role in supporting families with future planning, such as Family Relationship Services, respite centres and Carers Victoria. They usually do that through five or six sessions on various tasks of planning for the future. Those workshops vary in quality and comprehensiveness. Other agencies and practitioners, including Centrelink’s Financial Information Service, provide financial and legal advice which is equally variable, often expensive and not sensitive to disability and family issues. What we think is needed in terms of options and services to help people plan for the future is accessible, low-cost and nationally consistent mechanisms for the ongoing representation and support of people with a decision-making disability. Perhaps the Senate committee could have a role in encouraging state and territory jurisdictions to review existing mechanisms and make room for the appointment of substitute and supported positions. That would allow families of people with a disability to put in place current or anticipatory long-term representation arrangements for financial, medical and lifestyle decisions.

We think there is potential to expand the enduring power mechanisms to allow nomination of substitute decision makers for people with very severe decision-making disabilities or to allow the use of participatory supported decision making to give way to the views of the person with the disability and to assist them in making decisions. Of course, nominated attorneys, guardians or whatever they might be called will need information and capacity building in relation to their role and responsibilities.

We think there is a need to expand eligibility to increase the flexibility and reduce the complexity of special disability trusts. Also, we need to ensure the availability of low-cost legal and financial advice for people with a disability and their families, which could occur through community legal centres with workforce training and development and with fee subsidies for families of people with a disability. Those sorts of arrangements could be supplemented by online information and advice such as the QICPPP. I do not remember what that stands for, but it is the information service in Queensland.

There is a need to develop high quality and informed family workshops and information planning tools concerning future planning. This is probably Productivity Commission stuff, but we have long promoted the need to develop a national register of ageing parents with outreach support so that they are linked with the system and someone is monitoring their health and wellbeing and situation over time. We would see such a register as including a centralised database and having under it a whole lot of collaborative practices and procedures on future planning that are shared between agencies.

Finally, we want to emphasise that the needs of people with a psychiatric disability and their families must be addressed. Policy and practice research currently emphasises the need of ageing parents of people with an intellectual disability. There has been little systematic research in Australia about the needs of ageing people with a psychiatric disability and their families. While it is more common for those people to live away from the family home, many parents continue with an ongoing role of guidance and advice. They often provide financial and crisis assistance, and they are deeply concerned about the future. Access to housing and support are particularly limited for this group, and there is poor national data about the needs of older people with a psychiatric disability and their families. It means that there has not been a focus on the planning options and services that they might need. Thank you for listening. Lesley will contribute her perspective as the mother of a child with significant disabilities.

Ms Baker—Good morning. In January I will be 67 years old. I am the sole carer of my 33-year-old intellectually and physically disabled son, Benjamin. I have been his sole carer since his father left when he was 18 months old. My mother was my sole support and she died two years ago. My sister lives in America. My brother will give me no support at all. Ben is intellectually disabled. He does not speak and he displays some autistic tendencies. He can walk but not for distances, so he requires a wheelchair outside home. He also suffers from chronic sleep apnoea and he is one of the worst recorded cases worldwide. He requires 24-hour supervision and care which means virtually I toilet him, bathe him, feed him, dress him, teach him, entertain him and do everything else. He cannot be left alone in the house at any time and I have to sit next to him at night when he is going to sleep to watch for obstructions with the sleep apnoea. With all of that he is the most delightful young man with a whimsical sense of humour and he adores people.

He attends a day training centre five days a week. He leaves around 8.15 and gets home at four. He enjoys his life. He is very happy at the centre with his peers and his special workers and he enjoys coming home for tea, activities and bed. Holiday periods are a real trial for both of us. He misses his friends and I find I run out of ideas and energy caring for him 24 hours a day, seven days a week with only the 20 hours of holiday respite I receive because there are very few holiday programs for the intellectually disabled. I receive normally approximately 24 hours of regular in home respite per week. The rest of the time I am on my own. I have the eight hours a day that he is away to do everything else, household chores, household maintenance, gardening, banking, cooking, shopping, maintaining his accounts in accordance with VCAP requirements, meeting with support workers and agencies, constantly updating the endless paperwork. We get money from government, support agencies, educational facilities.

I do get one night a week to possibly go to the movies and, if I do go, I go alone. Older friends have drifted away because they now have their retirement and their grandchildren to look forward to. My parent friends are equally confined to barracks. Most of my social interaction is with the carers who come in to look after Ben. I have had a rotating workforce of literally almost hundreds of carers over the years, so it is hardly surprising I live basically in social isolation. Caring for Ben has also taken a physical toll. I am currently on the waiting list for a complete shoulder reconstruction but I am on the list behind a lot of people who can afford private health insurance and who have no-one waiting for caring. However, I will not be able to have that operation unless I can find the funding for care for Ben during my rehabilitation.

Certainly, for those of us who are caring for adult children still at home there is no retirement date, there is no superannuation. We gave away our careers and money many years ago. Our reward for years of care really is the agony of wondering what the hell is going to happen to them when we are no longer around. I am also Ben’s advocate but that is becoming more difficult now with the emphasis being on independence for the disabled. Now it is true that most disabled and many intellectually disabled people are quite capable of decision making for their futures and that is the way it should be. However, for the more seriously disabled such as Ben his input is impossible and parents or caring families are the only ones who can really advocate for them. I am the only one who can interpret what Ben wants, what he needs or is comfortable with, and what he is afraid of, and I maintain my right to speak for him.

The future for both of us really cannot be taken any further than the fact that I will be at home this afternoon to get him off the bus. Despite being 12 years on the urgent needs for housing list, he has never had an offer and there is no reason to suppose he will get an offer within the next 12 years because of a massive shortfall in housing. When the call does come from an impersonal voice we will be given an address and a contact phone number for a house that we will not be familiar with nor with any of its occupants. We will just be given a date and have to take it from there. Any of you that have adult children, I would like you to go to wherever they live, pack them a suitcase, drive them to a house they have never seen, take them in, introduce them to people they have never met and then inform them that this is their home for life and they have no choice but to remain there. I really do not think it would be long before the Human Rights Commission was involved. Why then is it acceptable to do that to those who least understand and are most vulnerable? I do not want to hear of any more young people, and I get upset, passing away not long after going into care and often their parents following them. I do not want that for my son.

Intellectual disability does not mean stupidity. It does not mean anywhere will do. He has got the same hopes, likes and fears as any other young man. He just cannot express them clearly. But one thing he does not have is a concept of the future. He has no concept of death or loss or that some day he will be without me. It is impossible to inform him that one day he will live with other people and that on another day I simply will not be there.

I want the right to choose with him the type of housing he would be most suited to, long before he has to go in so that he can become familiar with the people, the surroundings and the philosophy so that when the time comes it will be as easy for him as possible. The separation for him is going to be frightening and for me it is going to be equally bad, but it will be less so if he is familiar with where he is going. In a rich country like this it really is a condemnation of successive governments who have ignored the need. Where are the choices? Where are the beds? Can we choose between an individual house in a suburb or perhaps a village lifestyle? He will retire or he is being encouraged to go to retirement villages where the peer group have got similar interests and facilities can be shared. Why can't those disabled who need community care or desire it go to similar villages, possibly alongside the retirement villages, where aged parents in the care.

And rather than sitting in this thing, I would like to invite anybody who would care to to come and spend some time with Ben and me to deal first-hand with the lifestyle. You will get far greater insight. Thank you for listening.

CHAIR—Thank you for sharing that. I know it is very difficult in a public environment to tell personal stories, but it is absolutely invaluable to us to hear first-hand stories. Nothing speaks better than people's personal stories.

Ms Baker—Nobody knows, except us.

Senator BOYCE—I should probably add at this stage that I have a 26-year-old daughter with an intellectual disability, so I can appreciate some of the issues that you are going through.

Ms Baker—You know what it is like.

Senator BOYCE—Often in this sort of situation it is said that parents of people with disabilities can often talk about what they do not like, but to dream about what you want is so hard. Could you perhaps share with us what your dream would be and what would need to happen for it to work? I think we looked at the housing side of it; it is diabolical—but what else?

Ms Baker—Do you mean in the whole world of this, or instead of getting older?

Senator BOYCE—To you.

Ms Baker—To me, okay. To start off with I was on my own. Eventually, by accident, I found out that you could get council help. I was only part of the steering committees that allowed women to go back to work if they could. We still cannot get enough care, unless you have family care, to return to work if you need to. However, they are going to be that old that you begin to realise that somewhere down the track they are going to need housing care—that disabilities and the family structure are such that some day they are going to have to live with someone else. I knew that in my family nobody would ever take Ben on and God help him if he had to go to them quite frankly. So there is really no reason for not projecting ahead.

Ben has been on a list of some description since he was 13. There is a need to know. And then there are different philosophies and different styles. There are people who would like an individual house in the suburbs. For my son, the problem with that with his disability is that he would virtually be in a prison with four or five other people and go his day centres. Whereas with a more or less village style you know you might be able to share a flat or a house with two or three people, but you may not socialise with them. In village style accommodation they could socialise out in the grounds. This type of setting would be best for him. Others would do much better being independent with perhaps somewhere in the facility where they could get help. I would want a lot more care and emotional backup than we have. Single parents are a lot worse off than those who have partners. We also get carers who, although they may have done some sort of six-week course know very little. And I cannot tell you the number of people I have trained over the years.

Senator BOYCE—Who know very little about disability or about care?

Ms Baker—They know very little about what they are doing. But it is also difficult for them. I know the carers coming from Yooralla at one point had done the six-week training course, they came in and had absolutely no idea how to change an incontinence pad, they had no idea how to bath him. I said, ‘What are you training them with?’ The training was more like making choices like would you let them go on the scenic railway—those sorts of ethical choices, not the practical ones. I have had carers ring me to say that he had got out of the car and they could not get him to go back in, what should they do. You just toss your head and say, ‘Try this’. It is a minefield. You get carers coming in because you may, for instance, have made arrangements to go somewhere quite important and you can get a phone call within half an hour to say, ‘Sorry, they’re sick, they’re not coming.’ If we, as parents, cancel a shift for any reason with less than four hours notice, we get charged, and yet the carers can cancel or just not turn up and we get no credit for that.

Senator BOYCE—Is that common?

Ms Baker—Yes, that is common.

Senator BOYCE—Let us do the transition thing first. You talked about needing a lot of time for Ben to get comfortable with moving out somewhere. Your submission, and quite a few others, suggested transition planning sessions, and I think one even suggested a 12-month transition plan, and that was sometimes in relation to retiring from a disability enterprise. Would 12 months be long enough? What would happen? Who would fund it?

Ms Baker—If I had anything the way I would like it, say at around 12 or 13 you could pick a style or a management style. I do not suppose it would be possible to pick an individual house, because you would have no idea how long the current tenants are going to be there for, that sort of thing, but you could pick the style.

Senator BOYCE—Do you mean a type of housing?

Ms Baker—Yes, the type of housing, but also the type of management—everybody is different: the DHS run them differently to Yooralla, Yooralla runs them differently to Scope—so if they could visit a couple of houses they get to know people who are in there and the staff get to know them. One of the most frightening things for these guys is to know—with Ben with no speech, would anybody know what he wants and what he is talking about? It takes a long time to do that, to become familiar with that. I know the Jewish welfare housing, a lot of them take many months of transition just going and being in the headquarters, so the various staff come in so that eventually he is confident that, okay, he has lived with whoever it might be but they know him, they know what he wants, as far as they can do. That is what is required. I would say 12 months would be ideal, but often people have been put in houses and they are given one week and then told to not come back for two weeks. They have to leave the child, that’s it, boom.

Senator BOYCE—And do not come back for two weeks?

Ms Baker—And do not come back for two weeks. We do not want you here.

Ms Pierce—It still happens.

Ms Baker—Yes, that happens all the time.

Senator BOYCE—Sorry, parents and families are told not to come back for two weeks?

Ms Baker—You can be given a house, you are given an address and you go. If you do not accept that, you go back onto the end of the waiting list. But once you get there, depending on whoever is in charge, they will say, ‘Okay, yes, you can come in with them for a week, introduce them for a week, and then we don’t want to see you for two weeks or a month.’

Senator BOYCE—Sort of the technique you use with puppies, I guess.

Ms Baker—Yes.

Ms Pierce—One of the issues—again, it is about resources and what the Productivity Commission will do, we hope—that would be helpful to families, I think, is the possibility of planning together with their son’s or daughter’s peers. So instead of filing people into holes—putting people into places with carved-in facilities—facilities, supports and services are moulded around a group of peers. That says a lot about money, but that would be incredibly reassuring in that there is a group of people who know one another and who have positive relationships with one another.

Senator BOYCE—For instance, some people from the day service that Ben uses might be the group you talk about.

Ms Baker—Yes. I tend to think in terms of ‘if I could have anything I want’. Given the current system, quite frankly I have no idea, if and when the offer comes, how I am going to do it. I am a coward and I run from it, but I am thinking, ‘Okay, what could I do?’ The best way if that happened would be for me to move in with him and share his room with him on a stretcher—whatever—for a couple of weeks so that it becomes like his family home. Then gradually I would not be there for one night or two nights and would do it that way to integrate him. That is another way to do it.

The other thing I thought of with costing—I tend to think of costing—is that I have a house that, because my mother was there, could house four children plus me plus an overnight carer. So, in my home now, there are four bedrooms waiting to be used. With carers coming in, I become the overnight carer for them all. I am their overnight carer, so you do not have to pay overnight staff. If you get morning staff and afternoon staff, Ben becomes part of a group. Then, when I go—when I am really decrepit, I can go to a retirement village—Ben is with a known group with known carers, and if they all move then they move together. That would save a lot of money. Imagine if the government bought the house out, or whatever it was.

Senator BOYCE—The question at the end of that, in terms of support and sustainability, is: who keeps that happening for you once you are not there?

Ms Baker—Virtually, the roles would be that Ben is there and I am there; you would have staff coming in to cater for the others morning and afternoon, till 10 o'clock at night. I then would be there all night to cover the costs of anybody that got up or needed care. So I am the overnight carer. When I can no longer do that, I move out and then you need an overnight shift carer.

Senator BOYCE—What happens in the circumstances where the carer rings up sick and cannot come and things like that? If you are somewhere where you simply cannot care anymore, what sustains that plan?

Ms Baker—Then it would become a full-time residential. Once I am not there, that would become a DHS run residential, with staffing the same as for anybody else, or they might choose to move them into a DHS house, but as a familiar group.

Ms Pierce—Some families in Victoria have banded together with individual support packages that allow support to a small group of people, and the governance of that—what is essentially a residential facility or residential home—is negotiated with a local service provider. So ongoing responsibility is taken by that service provider. I am not quite sure of the scale of those sorts of models, but there are a number that have happened.

CHAIR—I am conscious of time, so I might just go to Senator Brown.

Senator CAROL BROWN—I want to get some more information from Ms Pierce. You talked about there being a lack of information or piecemeal information. You need to have a knowledge of legal requirements, local regulations and state regulations. You talked about needing an accessible, low-cost national mechanism. Can you explain exactly what you mean by that? How would you see this national information centre, and what services do you think it should provide? You mentioned community legal centres as well, so I do not know whether you were talking about just one national centre that can provide—

Ms Pierce—No, I think it needs to be local and accessible. I think we need to ensure that families are getting good legal and financial advice. I think that, currently, it is hit or miss. If you go to your solicitor saying, 'I want to think about my will and how I can best set up things for my son or daughter,' you are likely to get a whole range of conflicting advice from people who really are not sensitive to that; they have not dealt with that issue before. So I think having specialist legal and financial advisers in the mainstream system would really help families to find someone who can help them with the issues that confront them.

That is different from having a mechanism where families can appoint someone to oversee the affairs of their sons or daughters. I think that will have to be through state jurisdictions, but a national framework or something that puts that in place would be really helpful. We know with that we are swimming against the tide, but that does not mean that what we are saying is not important, because it really is. The moves to harmonise powers of attorney and so on, and the focus on capacity are very different to what we are saying. We are saying there is a group of people here for whom we need to have special mechanisms.

Senator CAROL BROWN—I understand the wish to have local information; but people’s circumstances vary, so they will need to source different information and they will need to get different advice.

Ms Pierce—Yes, absolutely.

Senator CAROL BROWN—How do you think that will be triggered? Are you saying there should be some place you can go that can direct you into other areas? You talked about Centrelink and their regulations, and a home being purchased which had an impact on the parents’ own financial future. I am just trying to flesh out exactly how you think it might work.

Ms Pierce—That is a really hard question. We have this notion of a register of ageing parents with outreach support. I would feel that one of its functions would be to support families to plan for the future. That would be locally or regionally based, something like that. Underwriting it would be protocols and procedures shared across agencies, and a real understanding of what support families can get from whom. So it would combine the kind of information about general planning issues that is readily available, though not necessarily high quality, with the financial and legal specialist advice. You could support that with website advice, I think, and build it up over time, with families being able to share experiences and educate one another online—that sort of stuff.

Senator CAROL BROWN—Okay. Thank you.

Ms Pierce—Does that answer your question clearly enough?

Senator CAROL BROWN—Yes, I do understand what you mean. Thanks.

CHAIR—I have one final question, because we are just about out of time. The concept of the register of parents—how do you see that operating?

Ms Pierce—There are many older families who are in touch with the service system and others who are not. Some have case managers; some do not. But those who are in touch with the service system usually have a trusted worker that they relate to. So I would see a register being a tool to ensure that each known family has a key contact who maintains contact at regular intervals so they can monitor the health and wellbeing of the person with a disability and their parent, and encourage them to plan for the future and resource them to do so. It is that sort of notion.

Ms Baker—There are many parents I know who, as they get older literally bury their heads in the sand. They wish it would all go away. We get our information in a piecemeal fashion. We get a bit in here and catching up with what on earth is going on at any one time is extremely difficult. There are parents who are not hooked up, do not know of things and will not go to meetings. It all gets too overwhelming after a while.

CHAIR—So this is a way you could provide information—network people together but keep them updated and have them access the sorts of services we have been talking about.

Ms Baker—Yes. Keep a track on those we know are on the register but not off.

CHAIR—Accessing services?

Ms Baker—Yes, so that you could—

CHAIR—I am from WA and know many people—I call it the race to the bottom—

Senator BOYCE—It is a revolving door race to the bottom.

CHAIR—You have to keep telling stories that are worse and worse, and if your story is the worst then you get services. Many people in our process drop out. A lot of them do not contact in the first place and others drop out. We do not have any idea, really, of the number of families and parents.

Ms Pierce—It is like that in Victoria. We have a mechanism called the Disability Support Register, which is the waiting list for housing and support. We cannot count around the state, but I think that the department feels that most ageing families with needs are registered on the DSR. We know that of the 60 families that Respite Connections supports there are about four who are. We have people with one or the other parent with dementia. We have people on walking frames and in wheelchairs who are not on the DSR because they have given up and they believe there is not going to be a place for them. They know that they are managing in a fashion now—they are not in crisis—so they will not get a look-in. That is a very difficult position for families to be in.

Senator BOYCE—You may not be able to answer this now but I am happy to put this on notice. Tell me if you cannot answer it. You talk quite a lot about the guardianship problems you have experienced. Are you aware of the situation in other states? Is Carers Australia doing anything in this area?

Ms Pierce—I think Carers Australia are loaded up with other things. I do have a notion of other states, but I did that work a couple of years so I do not remember it. I think it is all fairly similar. Can we take that on notice?

Senator BOYCE—Yes.

Ms Pierce—I think one state has a sort of slightly more flexible option, but I will have to redo the work.

CHAIR—Thank you very much for both your submissions and your oral evidence. We very much appreciate it.

Proceedings suspended from 12.15 pm to 1.15 pm

KACZOREK, Ms Sibylle, Executive Officer, National Ethnic Disability Alliance

WILLIAMS, Mrs Christine Anna, Consumer Representative, National Ethnic Disability Alliance

CHAIR—I welcome representatives of the National Ethnic Disability Alliance. I understand that you have been given information on parliamentary privilege and the protection of witnesses and evidence. If you need a little reminder then Tim, our secretary, apparently has some more information there just in case you want to catch up. We have your submission, which is numbered 26. I invite either or both of you, if you want to, to make an opening statement, and then we will ask you some questions. We will try and make it as painless as possible for your first time, Mrs Williams.

Mrs Williams—Bless you! 'Christine' is fine, thank you.

Ms Kaczorek—Thank you very much for giving us the opportunity to present here today in addition to our submission. I will be starting off with an opening statement, and then Christine, who is a consumer representative but who is also on the management committee of our Victorian member organisation, will be following up with a brief statement as well.

Just to recap, the National Ethnic Disability Alliance is the national peak organisation representing the rights and interests of people from a non-English-speaking background with disability and their families and carers throughout Australia. NEDA is funded by the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs to provide policy advice to the Australian government and other agencies on national issues affecting people from a non-English speaking background with disability and their families and carers. This presentation is in addition to our submission from May 2010. Rather than repeating the issues in the written submission, I will highlight points that NEDA considers as critical for any consideration by the committee and that were not covered previously or were only touched on. This presentation will address the four discussion areas of the terms of reference.

I will start off with 'other matters'. The committee has to accept the fact that people from a non-English-speaking background with disabilities and their families and carers have been neglected in terms of recognition and reporting as well as in policy, program design and service delivery. NEDA's own estimates are that there are around one million people from non-English-speaking backgrounds with disability in Australia. That makes one in four of the general population of people with disability. The available data, especially as it relates to the SDAC—the Survey of Disability, Ageing and Carers—is inadequate in its data collection in terms of the sampling size and the bias towards the English-speaking population and reporting. As it stands, the SDAC fails to capture second and subsequent generations of people from a non-English-speaking background, thus ignoring the fact that cultural traditions, whether through custom, language, faith or gender based values and practices, impact on people's wellbeing and their quality of life. The SDAC is also culturally insensitive to non-Anglo concepts. For instance, the notion of a carer is not existent in some cultures and thus may not capture carers from a non-English-speaking background, as they do not identify as such. For instance, some people may consider their role as a natural duty rather than as a caring duty. Equally, the concept of 'primary carer'—which equally is discussed in the SDAC—may not be recognised by some cultures, who would see their responsibility as a shared responsibility. This is particularly so for cultural groups who have less of an individualist approach to life.

NEDA and its member organisations have been advocating with the Australian Bureau of Statistics to address these shortcomings, with no success at this stage. We reiterate here our commitment to participate in improving the data design and the collection methodology. NEDA urge the committee to accept that the starting point of any planning framework is the interdependency of the needs of people with disability and the needs of carers. NEDA contend that, the more empowered and independent people with disability are, the fewer negative effects are experienced by carers. In this sense, NEDA believe that succession-planning needs to follow a strength rather than a deficit based model that strengthens the capabilities of the person with disability.

NEDA, through our own data analysis, have found that people from a non-English-speaking background develop disability at an earlier age than their Anglo-Australian counterparts. In addition, we have found that there appear to be more women with disability in the non-English-speaking community than men. Such findings, as pointed out before, are currently only identified through unfunded, non-government research—and, at this stage, I might also point out that NEDA is 1.8 staff—and often these issues are identified by chance. NEDA urge the committee to recommence dedicated research on the reality and the characteristics of people from non-English-speaking backgrounds with disability, their families and their carers, to inform government policy, planning and programs effectively.

I would like to make some points about choice and funding. There is little or no choice in planning options for people from non-English-speaking backgrounds with disability, their families and their carers. Choice is not a theoretical concept but a lived experience. Unless generic services offer communication strategies targeting the non-English-speaking community, including providing information in various languages and formats—that is, audio due to a disability, or illiteracy for that matter; free access to interpreters, over the telephone and onsite; multiculturally competent and multilingual staff; and outreach strategies in terms of information and servicing—choice remains merely a theory. In areas with high concentrations of communities with non-English-speaking backgrounds especially, dedicated services targeting the non-English-speaking community are necessary to undermine the current reality of inequity on access and service provision. This inequity is documented through the Productivity Commission reporting on government services.

In general, people from a non-English-speaking background ranked lower on the socioeconomic scale than their Anglo-Australian counterparts. The 10-year waiting period for access to the disability support pension exacerbates this poverty further. NEDA estimate that there are around 5,000 people with disability affected by this rule. Government expenditure of between $16 million, which is our minimum estimate, and $75 million, which is our maximum estimate, is entirely affordable and necessary to redress this situation. NEDA's advice is that the 10-year waiting period does not conform with the UN Convention on the Rights of Persons with Disabilities, and we urge the committee to recommend the abolishment of the 10-year waiting period, to remove one of the many barriers that migrants with disability face. Given the higher financial vulnerability of people from a non-English-speaking background with disability, this impacts on lower levels of personal savings and superannuation; thus initiatives such as special disability trusts have limited effect on the non-English-speaking population.

With regard to continued quality of life, the significant unmet need in disability services and the shortages of carers can be partially addressed by allowing carers of their choice to enter Australia through the carer visa (offshore) (subclass 116). This is currently limited by an Anglo-determined definition of ‘family’. In many cultures, there is no distinction between immediate and extended family members. By amending the definition of ‘family’ within the Migration Act 1958, the quality of life for people from a non-English-speaking background with disability can be improved. The quality of life for people from a non-English-speaking background with disability, their families and their carers is characterised by a lower access to the service system, usually at crisis point; and higher levels of poverty, higher reliance on ageing family carers and greater social isolation and exclusion. This situation will not change unless there is dedication to funding and to planning for a culturally competent service system and the removal of additional barriers as discussed.

In addition to the already noted options and services, NEDA needs to highlight the need to counter the myth that they take care of their own. This is common amongst generic and mainstream service providers. This myth is used to justify the lower uptake of services by people from non-English-speaking backgrounds with disability and by their families and carers. Research by NEDA and its member organisations demonstrates that the relative degree of stigma attached to disability appears similar across the non-English-speaking-background community and the Anglo-Australian community. This stigma leads to fewer contact and support networks, socially isolating families, and the impact is worse for women, who make up the majority of carers for people with disability in the non-English-speaking community. It is imperative that language and translation services are part of government funding and are compulsory for service budgets monitored against performance criteria. Equally imperative are cultural competence training and cultural communications strategies as parts of performance measures in funding agreements with health, disability and aged care providers.

Language-specific information distribution about choices and planning for the future needs to be facilitated through diverse access points, including ethnic community radio, television, newspapers and the existing community sector, such as that of the migrant resource centres, the ethnic community councils and also Centrelink and Medicare. There needs to be dedicated education and training campaigns, targeted at specific non-English-speaking communities, in which choices and planning for the future are explained and discussed. These campaigns need to incorporate empowerment for people with disability, such as budgeting and money management, as a key feature of succession planning.

Finally, NEDA believes that it is important to implement portability and flexibility of funds across disability and aged care to work towards a seamless transition. This would also require an amendment of the Aged Care Act 1997 to open eligibility to those under the age of 65.

Mrs Williams—I, formerly Krisha Anna Parachoniak, was born in war-torn Germany on 29 January 1950 to a Ukrainian mother and a Polish father and I have one older sibling. Our tiny family unit migrated to Australia around the time of my first birthday. Imagine the shock for my parents to be told to prepare for my funeral when I contracted polio at Bonegilla Migrant Camp shortly afterwards. But God had other plans.

The medical profession's word was law in those days, so Mother's desperate pleas to stop deforming her child's body fell on deaf ears. What would a woman who could not even speak English know! The excruciating physiotherapy I endured for the next 15 years would constitute child abuse and torture today. I can still hear my screams. For refusing to sign me over to the state, my parents took on the duty and burden of primary carers. Even within immigrant circles there was ostracism, one woman declaring it would have been better if I had died. Mother went to the grave believing that my disability was the result of her sinfulness. Her dying words to my husband were: 'Look after my little girl.' Two years later Mother's grave was opened for the coffin of my perfect, stillborn son, joined in early 2001 by my late husband's ashes. Culturally, their grave site is a sacred visiting place for me.

So, where am I at now? Still childless—my biological clock stopped ticking long ago; still a grieving widow with no-one in sight silly enough to take me on; still an incomplete quadriplegic, the challenges of which have steadily grown with age. This has become increasingly evident over the past few years. Some tasks are more difficult, with others simply beyond me now. Thank God I was able to design and build a fully accessible house. Thank God I live frugally and have some financial flexibility to afford the aids and supports I need. Thank God for the loving carers and friends I depend on every single day.

There was lots of time to cry and think while incarcerated at the Yooralla Hospital School for Crippled Children back in the 1950s, so to end my life in some care facility is not a scary thought. However, I would like true choices and control over what time I have left, without the worry that if admitted to a nursing home I no longer qualify for subsidised mobility equipment. I pray my future continues to be meaningful and that it will include ongoing community service within the disability self-help movement and the Salvation Army, treasured pilgrimages to the cemetery, Polish food, Christmas Eve celebrations with my sister, brother-in-law and their descendants and the company of good friends. That is not too much to ask for, is it? Which of four languages I revert to should dementia set in remains to be seen.

As Chairperson of DisAbility Connections Victoria I have obtained permission from our executive officer, Ms Helen Adams, to quote from her email of 23 November 2010 to the editor of the *Age*. Helen wrote in part: 'It was with great sadness that I read the article "Who is left to take the load when a life-long carer dies?" on 22 November 2010. As the Executive Officer of DisAbility Connections Victoria, this is a question that I hear on a regular basis. Carers of all ages all have the same concern. A couple of years ago DCV ran a forum about carers planning for the future. Of 45 carers in the room four—yes, four—told me they would euthanise their son or daughter if they knew they were about to die, rather than leave them to cope with the trauma of being left homeless and grieving.' My concern is that I suspect even larger numbers of carers from non-English-speaking backgrounds may consider that their only option.

Senator BOYCE—I might work through some of those things. But, firstly, Christine, you talked about the fact that if you went into a nursing home you would not be able to access subsidised mobility aids. Is that the case?

Mrs Williams—Yes. It was a real shock to me to find that out through my advocacy work, when I was approached by a family whose husband had gone into a nursing home. He was a very tall gentleman and he kept slipping out of the standard armchair they had in the nursing home. He was just too tall. He had had a stroke and he kept falling out. As a consequence of that

I made inquiries and found out that it is because equipment is state funded and nursing homes are federally funded. We are the meat in the sandwich.

Senator BOYCE—Presumably, it is based on the theory that the nursing home would have the equipment—and, if they do not, too bad.

Mrs Williams—That is right. When you look at my body, my equipment needs to pretty much be customised to the ability of my body.

Senator BOYCE—Yes. We have had quite a lot of evidence of other gaps in the system.

Senator CAROL BROWN—Is your recommendation asking that disability be included in the Aged Care Act because if that were done it would fix that problem?

Mrs Williams—I do not know. I think that was part of NEDA's submission. I have not gone into that side. From the lived experience, it is really frustrating when, for instance, concessions differ in different states. It is as if, once I go over the border, I can walk on water, and that is not the case. If and when I were to go into a nursing home my disability would go with me. It is not just the white hair and the lack of a husband! Does Hansard take down all the giggles too? That is good!

So that, for me, is a real quandary: what is going to happen? Will my family be asked to help? I do not have direct family. It is through my sister and her family. Will they be asked to pay for anything that I might need? I can no longer use calipers and crutches on any sort of regular basis. I can shuffle a few steps and that is about it, so, really, my upright days are over.

Ms Kaczorek—But, yes, you are correct that our position is that there has to be some seamless portability and accessibility between the two systems, the aged-care system and the disability system. So whatever arrangement needs to be there in order to make that possible should be made. It should be unthinkable that somebody who has access to aids and equipment now and who moves into a new system because of their age should suddenly lose that access to aids and equipment.

CHAIR—We have actually found the reverse happening too. When young people move out of nursing homes they cannot take the equipment that they have in the nursing home with them.

Mrs Williams—Through the aged-care system.

CHAIR—Yes, the equipment acquired through the aged-care system cannot be taken out.

Senator BOYCE—Part of this may well be about looking at how we define disability. We need to decide whether it is about people with long-term disabilities or age related disabilities. Is that a possibility as a starting point of some sort?

Ms Kaczorek—In some ways, it does not matter what the arrangement is as long as there is a seamless transition. But I want to re-emphasise the issue of the 10-year waiting period for DSP. At the moment in some states and territories there are aids and equipment regulations where accessibility to the DSP is an eligibility criteria. So at the moment there are people who are missing out on aids and equipment because they have not got the DSP, purely on the grounds that they have not been in Australia for 10 years.

Senator BOYCE—Are you able to give us any examples of that?

Ms Kaczorek—I can hand one in after the hearing today.

Senator BOYCE—That is fine. It is far more powerful if we are being told that a 10-year-old has to be carried around because the parents cannot access a wheelchair or whatever.

Ms Kaczorek—Just for your information, we just had a meeting with Jan McLucas, the Parliamentary Secretary for Disabilities and Carers, and one of our representatives at that hearing illustrated her point—and that is probably what I will be submitting as an example—that in her crucial years of being in Australia as a young person she did not have access to aids and equipment because of that ruling. That had a huge impact in her early years, because she migrated as a young person.

Mrs Williams—I remember the financial struggle that my parents had. As soon as they arrived in this country they took out HBA. You are probably all old enough to remember HBA. It is probably still around. But there was a qualifying period of three months or whatever and I contracted polio before that. So my parents were just left up the creek without a paddle. They came here with nothing, they had a child that they had to bury and then for the rest of their natural life they had to provide all the equipment that I needed. I was put into an iron lung just to try to survive. I remember trust funds coming to the party to help my parents with the equipment I needed. I needed a standing frame. I needed so much ironmongery just for my body to stand up. I remember the first time they put me in front of a mirror with my little crutches and full-length calipers and a body brace up to here because that was the only way my body could stand. I am sure that my parents' experience was not dissimilar from what a lot of people have endured and probably are enduring.

Senator BOYCE—Ms Kaczorek, you said you had had no success with the ABS in getting what you regard as meaningful data. Can you give us a very quick snapshot of what you mean there and what responses you have had.

Ms Kaczorek—The last SDAC was from 2009 and the data will be released early next year. In the lead up to that survey, NEDA made written submissions and submissions in person to the ABS in order to open up the definition of people from non-English-speaking backgrounds. That was unsuccessful, so we gave very concrete examples along the lines of the census data. The census data is very good at including and counting people from second and subsequent generations of non-English-speaking backgrounds. We made recommendations that the SDAC take on that identification in line with the census essentially, but that was unsuccessful. We also discussed the concept of primary carer and carer and whether there are other ways of being able to collect data that is less culturally sort of limited in terms of interpretation. So those submissions were made and they continue to be made.

The SDAC is every six years. The next one is in 2014. We are hoping there will be some improvement. One change was made between the 2003 and the 2009 SDACs, but we obviously have not seen the results of that yet. A question on language spoken at home was included.

However, we do not want to limit cultural identification to language either. There is a lot more to cultural practices and values than just language or country of birth. In 2003 it was just the country of birth and in 2009 it was country of birth and language spoken at home. Hopefully, in the next one, 2014-15, we will see some ancestry in there to be able to identify subsequent generation non-English-speaking backgrounders who may live incredibly traditional lives in Australia.

Mrs Williams—One thing on questionnaires that has irritated me all of my life is place of birth. I do not relate to German culture at all. It was an accident of birth because my parents had been captured and put into labour camps during the Second World War. In fact, it is a source of great distress to me every time I have to declare my place of birth. I was denied my mother’s heritage through the war circumstances and was raised with a Polish heritage. So if there is any heritage I relate to it is Polish, but that does not come out in any census questions that I answer, and I am sure I am not alone with all of that as well.

Senator BOYCE—So having someone think it might be a good idea to send a German-speaking person to your house to assist you would not really be very useful.

Mrs Williams—Probably about the only thing I could do now in German is swear at them.

Senator BOYCE—I noted you spoke about the definition of ‘carer’. That is certainly not something that is accepted within the English-speaking population either. My father is now in the position of being the family carer for my mother, but do not tell him, because he is her husband and he is doing what someone who loves someone does. He finds it bizarre that anyone would want to give him a label other than ‘husband’.

Mrs Williams—Those roles are fluid. Each and every one of us comes in and out of those roles. My husband had mesothelioma and when he was dying I was his carer. People would look at me and think how could I, but who would pay the bills, visit him in hospital every day, take him the paper and whatever else he needed and liaise with medical staff? Caring is more than just physical caring; caring is caring at every level—psychologically, emotionally and everything.

Senator BOYCE—Absolutely. You get to a very important point of this inquiry in saying that because it is not just about who provides the services; it is about who notices that you need the services and who monitors the quality of those services. That is part of it. Any thoughts you have on how we help people to plan for that would be good, particularly where talking about parents when they are not around anymore.

Mrs Williams—For me also there is a difficulty when we are talking about concepts. In lots of cultures disability does not exist as a concept; you are sick. As a Greek friend of mine says, when she was growing up people believed within her culture that she would get better or die. Even the term ‘teenager’ in some cultures does not exist. You are a child or an adult; there is no in-between. There is a need to understand these things. I am sure from the time when I started growing up in this country to the flow of migration now things have changed. There is an awful lot I do not know about some of the African immigrants and whoever because I do not have an opportunity to interact with them in the way I would like to.

Ms Kaczorek—That comes back to what I was trying to bring up in my opening statement as well. There have to be dedicated strategies and communication strategies in order to reach out to the communities. The empowerment of people with a disability is also critically important to the planning of ageing with disability.

Mrs Williams—It is extremely important to remember—when I give public talks I often remind people that it is my life. ‘If you my loved ones want to live it for me, you are doing me a disservice.’ Able-bodied people are allowed to make their own choices and their own mistakes so please be respectful enough to allow me to do the same, as long as I can make some form of informed choice. That can be as simple as offering someone cornflakes or pizza for breakfast. If they can point, ‘I want the pizza,’ let them have the pizza. It does not have to be mind-blowing decision making, just where a person can make a decision.

I know I get into a lot of hot water with parents because I am a great believer, knowing and having grown up in an ethnic home where my parents loved to me so much they wanted to protect me from the fear of failure, that without failure we do not develop and grow and mature. You are stifled emotionally, and in every way. Every child has a right to fail, including a child with a disability.

Senator FURNER—On the subject of communication and data you just made the point about that. I note in your submission, and it is quite relevant, you indicate that 73.8 per cent of NESB people do not have access to the internet. To be honest, I do not see that improving. I do not know how you educate people, not only from NESB but also in some circumstances the elderly, to move to internet usage. What can governments and organisations like yours do to improve that communication?

Ms Kaczorek—I was pointing out some of the issues. I think outreach is an incredibly critical approach to any communication strategies. That means that services and planners have to go out to the non-English-speaking communities where they are. There is a lot of word of mouth, but there is also a lot of education necessary in terms of what Christine was outlining earlier as far as the stigma within the communities. The reality is that, based on that stigma, people with disability are not necessarily engaged in their own community. In order to break that down, work is necessary in the multicultural non-English-speaking background communities as well. So I think outreach is one.

The internet will always remain one tool for reaching out in terms of information and communication but it cannot be relied on exclusively, especially not in a non-English-speaking community. That is where poverty comes in—the fact that non-English-speaking background communities, on a socioeconomic scale, are at the bottom. There are costs involved in communicating via the internet. I think that we probably will see changes as internet is taken up across the board, and I would suggest that figure will reduce, but it will still be significantly higher than for the English-speaking community.

Mrs Williams—I would like to add that my growing up experience is that my father suppressed my mother’s ability to gain educational experience. So, first of all, to use the internet you need some sort of literacy. My mother had been captured as a young teenager during the war so her education was cut short. She was a very intelligent woman innately but she did not have formal education. Within our home we were forbidden to speak English; you were not allowed.

Unless dad was at work, you could not speak English in our home, so what chance did mum have? She worked in a factory. What chance did she have of learning English? Her husband did not allow her to go to school at the weekend. I suspect there are a lot of cultures around where the male wants to be dominant and the way they retain that control is by suppressing the woman and her rights, and that worries me enormously.

Ms Kaczorek—I would like to make another point on the communications strategy. I think it would be very useful for service providers to have performance criteria and measures relating to how they reach out to the communities that they are serving. The census will provide data as to what the communities in a particular service provider’s geographical area are, so there can be quite concrete data and measures can be set up in order for services to reach out and to develop their own communication. That means engaging with the local communities, there is no way around that but at the moment we do not see that happening. We will not see that happening if it is going to remain a voluntary goodwill situation. I think there have to be targets, and there have to be performance measures in order to see any kind of improvement there. The access of the non-English-speaking community to services and provisions is significantly lower than for the English-speaking community.

Senator FURNER—You also mentioned that the figure for NESB people with disabilities is around one million. Is that figure understated?

Ms Kaczorek—That is the best data that we could come up with with the resources that we have working with volunteer data analysis and comparing census data, SDAC data and also general survey, GSS, data and trying to bring it all together on variables that were commonly shared. That is the figure we are working with. We do not have an exact figure. We are asking government to provide us with that figure and to allow data collection to be improved so that we can actually know what we are talking about.

Senator FURNER—If you have situations such as Christine identified with cultural beliefs of people being sick as opposed to being disabled that would naturally impair that figure as well, wouldn’t it?

Ms Kaczorek—If people are not identified, yes, for sure. There is a huge identification issue there. We also believe that the same applies for carers as well. There is an under identification issue there based on the definitions that we were talking about earlier.

Mrs Williams—Absolutely. Having grown up with a disability, I am very concerned that people within ethnic communities, within non-English-speaking background communities, are aware that they have rights and that their families are aware that they have rights because I do not want to be denied my right of free speech and that type of thing. I remember visiting family friends when I was growing up and suddenly someone from the back of the house was brought in. Because of my presence the disabled member of their family was allowed to come into view. That is in my living memory. I am only 60 years old.

Senator CAROL BROWN—In your opening statement you touched on the fact that NESB people develop disabilities at an earlier age. Could you provide some information as to why that occurs?

Ms Kaczorek—We did a data project which was a comparison of the different sets of data that were available. One of the findings that we noticed when we did the graphs was that people from a non-English-speaking background have an earlier onset of disability. We have assumptions about why that is the case, but in our first submission that we made in May we recommended to the committee that there needs to be some dedicated research on that. We suspect it has something to do with unsafe working practices but we cannot evidence that. That is our anecdotal suspicion. If that were true then there are also huge issues in prevention that we can actually address and target. Unless we know that and have the stories behind those figures, it is very hard to convince government to—

Senator BOYCE—I suggest that you bring that information to the attention of the Senate Standing Committee on Education, Employment and Workplace Relations. They would be a group that might be interested in that topic.

Senator CAROL BROWN—I think you were going there in your answer, but what sort of recommendation would you like to see that would assist to overcome that issue? What would you like to see this Senate committee recommend?

Ms Kaczorek—In the first instance, we are recommending dedicated research on that to find out whether it is true that there is an earlier onset of disability for the non-English-speaking community and to identify the reasons for that, and then, obviously, once that has happened, following up with dedicated prevention strategies.

CHAIR—Although that prevention is not necessarily going to help those who are ageing now. It is fair enough to stop it, but we have a lot of people who are likely to have already been or who are ageing earlier.

Mrs Williams—I think it is worth mentioning that, where I grew up, my parents and their friends were fodder for the manufacturing industry in the western suburbs of Melbourne. To this day, I believe there are still private sweatshops in non-English-speaking-background homes. There are cans of worms there; there really are.

Senator BOYCE—I want to go back to the comments you made and also the Multicultural Disability Advocacy Association made about the myth of ‘taking care of their own’. Given that that is a myth, what does succession planning look like or what should succession planning look like for—and this is very hard—the typical family that has a child with a disability from an NESB community?

Ms Kaczorek—I think it is a whole combination of things. It goes back to the points I made about strategies to empower the person with disability.

Senator BOYCE—But there are going to be people with disability who are not going to have good decision-making capacity of their own—

Ms Kaczorek—Sure.

Senator BOYCE—so it is about that spectrum, too, that we need to cover.

Ms Kaczorek—If we are talking about that particular group of people then we would argue for very, very dedicated communication strategies and reach-out strategies to bring it to the attention of the current carers, if we are using that term—to alert them to the fact that this is what is happening at the moment, that there need to be strategies put in place for succession planning and that we are engaging with the non-English-speaking community directly. I think we are trying to say that it has to be in addition to the mainstream and generic approaches. If there are only going to be the mainstream and generic approaches, these people will not be reached, there will not be any planning and they will be completely excluded from that process.

Mrs Williams—An independent advocate for the child is one way of doing it to ensure the child’s rights are met—

Senator BOYCE—Would that be through not-for-profit organisations funded by the government? Where would the independent advocate come from?

Mrs Williams—I have not even thought about it. It was just that while I was listening to the discussion I thought to myself: an independent voice for the child that cannot speak for itself, to make sure that their family is well aware of the child’s rights. The love of parents and families can be the most restrictive element in someone’s development. I will never forget when I went to London with my late husband. We were on the Underground, and I looked at this massive escalator, like I have never seen in my life, and I said to him, ‘Aren’t you going to lift me on?’ He said, ‘If you want to get out of here, you step on it.’ My father had always lifted me onto an escalator. I was used to that protection, and suddenly I had this man who said, ‘Well, if you want to go out, do it.’ And it was wonderful. Suddenly this little bird was blossoming.

Ms Kaczorek—In addition to that, we certainly argue for independent advocacy across all states and territories for the non-English-speaking community, which is currently not a given. Where we do have those advocacy organisations, in particular in WA and in New South Wales, Victoria and partly also in Queensland, we see that those organisations are inundated. But, where they do not exist, there is actually nowhere for people to go at the moment. So the independent advocacy for the non-English-speaking community is critical for that question.

Senator BOYCE—This is my last question. You talked about seamless transition into aged care or whatever. I am assuming that there are probably particular and extra problems with aged-care provision for people from non-English-speaking backgrounds anyway. If that is the case, what needs to happen to assist people with disabilities to go from community, home or whatever to aged care? You have 10 seconds! No, I am joking!

Ms Kaczorek—We would not say that the aged-care system at the moment serves the needs of people from non-English-speaking backgrounds effectively either, so it is not that we are saying that the aged-care sector at the moment has the solutions and therefore we need to model it on the aged-care system. Really it comes back to the points that were made earlier about having dedicated strategies and dedicated targets, having different ways of approaching communities from non-English-speaking backgrounds and bringing this all together into both sectors. The barriers are there for both sectors and they are equally there for both sectors.

Mrs Williams—Can I suggest cultural awareness and also cultural awareness of diversity within each culture. Even within the Polish community, I can still meet up with people who knew me as a child who will pat me patronisingly on the head: ‘There, there, dear.’ I have a university degree. I do not think I need to be patted on the head. I think the diversity within all groupings needs to be acknowledged and needs to be factored in, because what for me may not be a problem culturally—for instance, if I am having a bed bath, if it is a male carer it may not be a problem for me—for someone of a different faith, or who is Indigenous or whatever, might be a huge problem. So I think cultural awareness is extremely important.

Ms Kaczorek—I just want to add one point that I made in my opening statement—that is, the opening up of the Migration Act for carers of choice. That would go a long way for people. We constantly hear in consultations with consumers about the inability to have culturally competent, culturally aware or same-culture carers.

CHAIR—I think we will have to draw it to a close there as we have run over time. Thank you very much.

Mrs Williams—Thank you.

Ms Kaczorek—Thank you.

CHAIR—I think you said you were going to get some further information to us.

Ms Kaczorek—Yes, I will pass on further information.

CHAIR—Thank you very much.

Mrs Williams—Can we speak off the record? I want to know how Tim found my evidence. Are you interested?

CHAIR—Everything you say here is on record.

Mrs Williams—Oh, is it? Very good. Thank you, bless you. Thank you all. Enjoy your deliberations. I am glad it is you and not me!

[2.04 pm]

HAGILIASSIS, Dr Nick, Acting Head of Research, Scope (Victoria) Ltd

HEGGIE, Ms Diana, Chief Executive Officer, Scope (Victoria) Ltd

WILSON, Ms Jacqui, Project Adviser, People and Culture, Scope (Victoria) Ltd

CHAIR—Good afternoon. Thank you for coming. I understand that you have all been given information on parliamentary privilege and the protection of witnesses and evidence. Do you have anything to say about the capacity in which you appear today?

Ms Wilson—I am the people and culture adviser for Scope Business Enterprises.

CHAIR—We have your submission. It is numbered 17. I would like to invite one of you or all of you, if you feel so inclined, to make an opening statement, and then we will ask you some questions.

Ms Heggie—I might do that. I would like to congratulate everybody here on this wonderful inquiry into the planning options and service issues for people with a disability who are ageing. I think it is an excellent topic and one that does require extensive debate. We are delighted to have been asked here today, so I would like to acknowledge that.

Briefly, Scope is a Victorian based organisation. It is one of the largest disability providers here in Victoria and we support over 7,000 children and adults with disability. Our major focus is on the actual severe and complex end of disability, just so that you know. Today we will not be talking about early childhood or anything like that; we will be talking about the areas in Scope that ageing and a disability are impacted on.

In Victoria, people with a severe and profound disability number over 170,000 of people over the age of 65. So we are looking at this as being a fairly significant issue into future across Australia. In our submission we talked about three areas that we wanted to focus on. The first area was people with a disability who are ageing. The second was the ageing carers who are supporting people with a disability. And the third was the issues for service providers. We did build in some discussion around what some of the solutions are about the issues, too, which we intend to talk to today.

In terms of people with a disability themselves who are ageing the greatest pressure point for us as an organisation and for other disability providers here in Victoria is in the area of supported employment, or disability enterprises as it is called, which gets few resources from the Commonwealth government. This is an area where there is absolutely no space. There are no planning resources, no person centred planning, no case management resources and no pathways for people with a disability to go from retirement. So, even if somebody thought they would like to retire, there is nowhere to start to even think about it. When you think about that it is really significant. A large number of these people are living at home with elderly parents. Whilst the person with a disability sees this as work and going into work every day, they see that as actually respite for their sons or daughters. So the pressure on the person themselves who is out working to stay out work is enormous on two fronts. So it is a very, very important issue.

Of the 300 people we support, we have 60 people who are needing to look at alternatives. A very close business enterprise that supports over 260 have 80 people. That gives you some context about the urgency of this, yet there is this divide between Commonwealth and state in terms of whose responsibility this actually is. Who is responsible for this? Who is accountable? What are the targets? It is very simple in management planning but there is not that accountability, responsibility and targets clear at all in this space. That is probably an area of significant pressure.

In terms of the state and people who are in what we call ‘day services’ or in the day and lifestyle area, whilst they do receive individual packages of care now in this state, one could think that that would enable them to take their package of care and be supported if they wanted to retire. But, unfortunately, those packages of care are actually based on people doing things in groups. So, if I choose to retire and I have a significant disability, unless I am pulling three other people with me it is very difficult for me to retire. So we have issues there as well in respect of the execution of successful retirement options for people.

They are the key issues in respect of people with disabilities themselves that we would like addressed here today. In terms of the possible solutions for people with disabilities in this area I think it is very simple. At a very high level we need to, as I said, first of all decide and be very clear about the accountabilities and responsibilities for this. Whether it is state or Commonwealth, somebody has to take responsibility for the funding around this. They just have to because it will never happen and will not be executed unless we are clear.

We need to set up and need to allocate the resources to whoever is going to take on the person centred planning or the case management around this. We need to have dollars attached to somebody’s plan to enable them to be able to retire and, of course, select their agency or whatever it is and however they want to do it. As I say, I see it very simply but I am talking in the absence of resources and an acknowledgement that they must be there.

The other solution in respect of people with disabilities is the whole issue of housing and support. It is a very difficult issue and if you are actually ageing with a disability and you need long-term housing, perhaps there needs to be a look at what I call housing and support models for people who are ageing with a disability. I cannot be supported on my own because the current funding mechanisms do not allow that. I think there should be some look at housing and support as a totality for people with a disability, not necessarily a package, but similar maybe to aged care except smaller and more flexible models. I think that is another solution. People talk about it as ‘key ring’ or something like that with a big emphasis on supporting people’s health needs because we find that is a very big reason why families do not actually enable their sons or daughters with complex needs to be supported in the current system because their health needs are not being adequately met. They are some of the solutions around people with a disability.

The second one is the ageing carers issues who are supporting people with disabilities at home. I cannot emphasise enough the stress that these people are currently under. The figure we have is about 450 ageing carers who are supporting people with disabilities currently in their own home. If there were something that they felt really comfortable about they would look, perhaps, to transitioning.

Senator BOYCE—That is just within Scope?

Ms Heggie—Yes, just within Scope, so you have to multiply that out. We have not done the statistics across the state on this. The issues are overlapping a bit with people with disabilities themselves. Parents do not feel that the services in the system for people with complex needs are what they want. Yes, there are community living options for people, but they are restricted to five people living in a community based home with a sleepover type of arrangement. A lot of our families are saying, 'We're not prepared to let our son or daughter with very complex needs, with PEG feeds, with communication problems, with nobody really there to support their decision-making processes to be put into and placed in a system like that. We want more supported accommodation that looks after not only the community but the wellbeing, social inclusion, but the health needs. We actually do believe in many instances we need 24-hour support.' That is a very big issue; the housing and support that is out there.

There has to be more long-term planning for not only the person with the disability but also for the carer and it has to start earlier. We are inclined to wait until the parent says they are in crisis before we actually do this planning. It is crisis planning instead of this long-term planning. We need to build capacity of universal services to be able to assist with some of this. Somebody said to me, 'What does that look like?' We believe that perhaps a hub-and-spoke type arrangement would be really good. So you have specialist people who have knowledge of this ageing or disability at a central hub. Then the community services are supported by the specialist staff to enable them to be the universal service provider out there. They have somewhere to actually come back to in terms of getting the specialist support. That way you would get more confidence in terms of the ageing carers being able to let go and facilitate the life of the person, who might be 50 and is living with 80-year-old parents. It is just not healthy and is not what you or I would like in terms of our lives. So it is very important that we look to the capacity of the universal sector. And parents would be a lot happier.

In the emergency housing area, if a crisis happens the person with the disability ends up going into respite care facility. Last year in the north-western metropolitan region 50 per cent of our respite places were blocked up—it sounds awful saying 'blocked up'—and were unable to be used because of crises that had happened in ageing carers' homes and the person with the disability had to take the place for a year or two years. That meant all the other people that wanted to use respite were not able to use it because 50 per cent of our places were taken up with crises. We would suggest some emergency type or transition housing that the families knew was available if something should happen. That would be assistance for the ageing carers. A bit more of lifelong planning and stuff around decision making for people with a disability needs to be considered, too, in terms of their capacity to make decisions in respect of some of the choices that they make.

I am only going to speak for two more minutes. I am rushing so that you can ask questions. What are our issues as service providers? Our issues are all of their issues, in a way. There is respite, for example—places are taken up and then we have pressure from families saying, 'Why can't we access the service?' We have to try and explain that there is no planning and nowhere for people to go. These are ageing carers, and that is how this has happened. That is not what the respite services were set up for, so they get quite annoyed and angry about it.

We have an issue in our business enterprises area. People want to retire but cannot retire because there has been no planning, no resources and no capacity. We have young school leavers who want to come in and take the places but they cannot because those people cannot retire. The frustration level that you get in terms of that is really very significant. There are workforce development issues around ageing. A lot of people with complex needs age earlier than you or I do. A lot of research is being done on that. Instead of being 65 you actually have ageing signs coming in at 55. Our staff need assistance in terms of understanding that and the impact of the ageing issue overlaying on the disability issue. That is an issue for us. There is frustration with the bureaucratic side. I am not being negative about it; I am just saying that accountability, responsibility and lack of targets with respect to bureaucrats—who is responsible for this area or that area—is very frustrating for us. It is like handballing the responsibility all of the time. We would see that as another issue.

Housing models are very restrictive and do not meet the needs of high-level, complex disability with respect to ageing. That is frustrating because we have limited options for where people can go. And, as I said, regarding capacity building of the universal sector, we would see that as a great development if there were a type of hub-and-spoke model. That is my presentation.

CHAIR—Does anyone want to add anything else?

Dr Hagiliassis—You may have questions and we would be happy to input then.

Senator BOYCE—I would like to follow up on a couple of things that you mentioned. You talked about ‘key ring’. Could you explain what ‘key ring’ is?

Ms Heggie—There are jargon words in the sector. I would agree that they are a bit frustrating. It is the notion where you might have three or four people living here who are ageing with a disability and, less than a kilometre down the road, there is another group and another group. That enables service provision to those homes to be managed much more flexibly and efficiently. Instead of big institutions like they had in the past—

Senator BOYCE—So it is cluster housing at a distance, so to speak.

Ms Heggie—It is cluster housing, provided it is within the context of the community—near shops, trains, public transport and all of that. It brings with it some benefits in terms of being able to get your carers to manage your care.

Senator BOYCE—In your submission you spoke about a retirement resource developed by Wodonga TAFE. Would you be able to provide a copy of that to the committee—not now but some time?

Ms Wilson—Yes.

Senator BOYCE—Was that is done with your input?

Ms Wilson—That was done through FaHCSIA and Wodonga TAFE. It was all about retirement planning. It was more like a workbook.

Senator BOYCE—Does it follow on from the FaHCSIA work on getting started and—

Ms Wilson—Pretty much. It is part of that support documentation.

Senator BOYCE—The situation that Endeavour faced in Queensland was that people were living in supported accommodation facilities who could not retire because no-one could find any funding to provide support for them so that they could stay home during the day, despite the fact that that may well have been what they wanted to do. Is that the situation in Victoria?

Ms Heggie—That is a big issue for us as well. It is the people who are currently in supported accommodation who want to retire out of the businesses. People who are not living with their parents—they are living in supported accommodation—cannot go home, either, because the state has not agreed to fund them while they are at home. It is the same issue about sorting out who is responsible for what. It is very significant here in Victoria across the sector.

Senator BOYCE—There is a preponderance of older workers in your business services. But you have explained that by saying that until you can work out how people can retire you cannot get younger people in. Is that is why that has happened?

Ms Heggie—That is the problem.

Senator CAROL BROWN—Today we have had quite a bit of discussion about the retirement age going from 65 to 67. You mentioned in your submission early onset ageing. Do you have a view on what the retirement age should be for people with a disability?

Ms Heggie—I do not have a view about there being a set age. In this area of complex disability we have people with a disability who are as young as 50 but who have very significant signs of ageing. It is more at the complex end. We would like to some recognition or acknowledgement of the fact that a person who is 50 with significant signs of ageing and who cannot work any more needs to retire. We should be able to support them.

Dr Hagiliassis—Ageing for people with developmental disabilities in particular is associated with a complex range of medical, health and related needs. One of the issues that we face as a service provider is identifying the different factors that play out for people as they age with a disability. As I am sure that you have heard over the course of the day, people age on a spectrum. Our view is that, if we are considering that question of that the threshold is in terms of aging, it needs to come back to the individual and their set of circumstances. I would call for criteria that are based on functional changes for that individual but also on the perceptions of that individual and the people who care for that individual in terms of how they are ageing and what impact ageing is having on them. So there should be a combination—functional criteria and criteria based on perceptions.

Senator CAROL BROWN—Some flexibility; moving away from chronological age criteria.

Dr Hagiliassis—To add to that, we need to build on our range of tools and resources for making such decisions. As it currently stands, there are not sufficient resources to adequately allow us to make informed and accurate decisions about ageing issues for people with disabilities. There needs to be some work in the tools and instruments development space in a way that captures both functional change and self-perceived change.

Senator BOYCE—There are people who would like to retire. But there is also a group of people who do not want to retire, not because they are enjoying work but because that is there only social contact outside of the family. Are you aware of this? What would help those people with that issue?

Ms Wilson—We have that kind of employee as well. That typically stems from the fact that we have been the only service provider that they have had contact with while they have been working, which could have been 30 years. That is why the planning for and transition to retirement needs to be managed in a way that allows us to help them to identify other suitable services. The fear of where they are going to go to and what that will look like becomes a barrier to them wanting to leave. We have what we call past employees associations. People come back and participate within the work space, so they maintain their friendships. That has had a positive effect on the people who we are looking to move out, because they see that other people have found services that are more appropriate for the stage of life that they are in and they have kept contact with people who they have built friendships with over their years of service. It is a process of engaging with the person and their family early enough and creating a pathway that leads to the right destination. That has been a factor in our success there.

Senator BOYCE—I think you have suggested a 12-month transition program.

Ms Wilson—That is right.

Senator BOYCE—I was interested to note that you made the point that 10 years ago only five per cent of residents in supported accommodation had gastric feeding tubes and now it is 20 per cent. Is that about people with more complex needs going into supported accommodation?

Ms Heggie—I think the issue of PEG feeding in itself is very complex. I know that the local council workers, for example, will not actually provide PEG feeding support. We are one of the few agencies that actually do provide it and do provide the training to staff. So I guess it has become known that we will provide support to people with those kinds of complex needs. That has been why we have had an increase in referral.

Senator BOYCE—This would include people with tracheotomies too, who often have difficulty finding a carer to come to the home.

Ms Heggie—Yes. We do not have too many people with tracheotomies. We may have one or two. It is the PEG feeding that we have had a huge increase in. It is more because we have said that we have the capacity to do it and are prepared to take it on.

Senator BOYCE—And the fact that carers under HACC or other programs will not do it anymore.

Ms Heggie—Yes.

Senator FURNER—I have a couple of questions with regard to your profile of Wan. You were privy to some of the comments made by the previous witness. I am wondering whether any of the NESB issues were identified with Wan in particular.

Dr Hagiliassis—Wan was one of our case studies, the profile of a lady with a disability who has been involved with Scope in a range of capacities and some of the issues that she has faced in accessing services based on choice and preference. Could you clarify your question?

Senator FURNER—I was asking whether there were any issues associated with a non-English-speaking background. I am assuming that she came from a non-English-speaking background.

Dr Hagiliassis—That is correct.

Senator FURNER—I am interested in the sorts of issues she faced because I do not think you really identified those in your profile of her.

Dr Hagiliassis—Perhaps I can take a step back. At Scope we support many families from culturally and linguistically diverse backgrounds. I think in Wan's case that was less of an issue. We may be able to comment on the CALD factors in relation to the broader population that we support, but Wan was a fairly empowered individual and someone for whom the CALD factors were not as significant as may be the case for others.

Senator FURNER—The expense in the aged-care facility that she lived in for two months—$2,000 per month—is that an average figure? Can you comment on that at all?

Dr Hagiliassis—I cannot.

Ms Heggie—I could get back to you on that.

Senator FURNER—Okay.

Senator CAROL BROWN—There has been a lot of discussion about Commonwealth funding and state funding and who is responsible for what in terms of disability and ageing. Would you like to share a view on the issues relating to Commonwealth funding being only for aged care and state funding being for disability? That is obviously not including employment services and income support.

Ms Heggie—There does not seem to be anybody who is responsible for this space that we are talking about today. There really is not. If a person is 65 and is eligible for a nursing home or to go into aged care, they go through a certain process, but we are not talking about that. We are talking about people who could be 57 or 61 and have significant signs of ageing. Where do they go? They are in supported employment currently. The state government does not see that as their responsibility. They say, 'They're in work. That's not our responsibility.'

We need to sort the blurring of accountabilities around that. The way it currently is is not working. Yes, if you want to go into a nursing home you can be assessed, but that is not what they want. This is about lifelong planning about ‘I need to retire’. I have got no resources tagged to me in my place of work; that is a workplace. So if I want to retire and I actually need some support—I could need support in decision making and a whole range of things—there is no avenue for me to even begin. We need to sort it out. If you are asking me where it should lie, I do not necessarily mind where it lies. But I feel that we need to know where it is going to lie.

Senator CAROL BROWN—What can we do? What recommendations would you like to see?

Ms Heggie—If you think about service delivery—and I think about it—service delivery is always best delivered as near to the individual as possible. I guess, if you use that as a rule of thumb in respect of delivery of services, as near to the individual as possible is probably the best. There is no point in having a resource on planning that is sitting up in Darwin when the person is having services down in Victoria. Do you know what I am saying?

Senator CAROL BROWN—Yes.

Ms Heggie—I think the nearer to the individual the better. It does not matter whether it is funded by the Commonwealth, by the state or whether it goes to a non-government agency—wherever—as long as we are clear and people know where it is and what the resources are for planning for retirement for people with a disability who are ageing. ‘Here is how it gets implemented and here is the pathway’—that would just make it a whole lot easier.

Senator BOYCE—You were talking earlier, Ms Heggie, about individualised funding not really being individualised funding. Is that because the amount of support that you get is not sufficient to provide the proper care for one person and you have to aggregate it to get a decent package?

Ms Heggie—I will give you an example. Right across Victoria we have what we call a day and lifestyle program for people with disabilities—the people who cannot work, the people with high needs. Originally we received a block grant from the state government to facilitate day and lifestyle options for 600 people. Earlier in the year that block grant got divvied up between 605 people, and the 605 people were let know what their package was. Is that based on people’s real needs for their daytime support? It is not, really. I think the way it is done is that it is about one to five or one to four. So the whole time you have got to be managing the package. For a person’s disability to have support between the hours of nine and four everyday, if that is what the family and the person wants, it is predicated on you juggling that money to make it work. But if somebody who needs one-on-one personal care wanted an individual package from nine to four, of course that is going to be a lot more money.

Senator BOYCE—A lot more money than that individual is currently getting?

Ms Heggie—Yes, a lot more money than that individual is currently getting.

Senator BOYCE—So it is about the quantum that was in the pie and how the pie was divvied.

Ms Heggie—Yes, exactly. We all understand that. That is how a lot of allocations get done. The quantum does not get bigger and bigger. The quantum is here and we need to be realistic about that. But for somebody with very complex needs who wants to come out of a day area or a business area—the business area is less resourced even than the state day area—unless they are in a group or can cluster together, it is nearly impossible.

Senator BOYCE—So that they get some synergies in their service delivery?

Ms Heggie—Yes.

Senator BOYCE—I understand the point you are making there. I share the concerns of a lot of people as to why they wanted block funding to stop, because I think there were some organisations that were almost holding families and individuals to ransom because of the block funding.

Ms Heggie—We do not mind. The individual funding is great. There is nothing wrong with it.

Senator BOYCE—It is just the quantum of it.

Ms Heggie—The quantum is always the issue.

Senator BOYCE—The other thing is, you have given the example of Mr and Mrs H. and you talked about the reluctance of ageing parents, often, to plan for what is going to happen to their adult child with a disability once they cannot care for them anymore. It is quite interesting that we do not actually have a word for ‘adult child’ in English, so you have to keep saying ‘ adult children’. What would you like to see there?

Ms Heggie—I actually know them personally. They are in their 70s and their daughter is in her late 40s. She has a very significant disability; she cannot communicate and has to have PEG feeding. Mrs H. has said to me on many occasions: ‘Diana, my big fear, my big problem, is: what’s out there? And I’ve looked at a lot.’ She says, ‘The housing and support arrangements and models that are out there just won’t meet her needs to my satisfaction.’ Her daughter’s healthcare needs just are not and cannot be adequately met in the current disability system, because there is not, and has not been for a long time, a recognition of social models of care.

So it is around social and community models, and community inclusion. There has been a forgetting of the fact that some of these people have very significant health needs. So Mrs H. is not happy that the system cannot meet her daughter’s needs. She does not want her daughter to go into a sort of hospitalised, nursing, sick environment either. What she really wanted was a community-based facility that had in it expertise in and capability for both health and disability. She wanted a facility that would give her daughter 24-hour care—and not just somebody sleeping over in the back of the house—because she has spent her life hopping up at night. She has a little monitor, and she gets up three or four times in the night to meet her daughter’s needs. So she does not feel that the current system would satisfy her daughter’s needs. And there is quite a cohort of people like that.

Senator BOYCE—What should we be doing to help them? I am not talking about providing exactly that service that meets their needs but about what we can be doing to help them to think about planning.

Ms Heggie—I think we have to start going in there early on, but we also have to be able to demonstrate some of those things. I do not think it is unreasonable of her to expect that her daughter’s needs should be met. She is not unreasonable; she is not asking for the world. I think people need to do early planning—so not in their late 70s but back, say, in their early 60s. We also need to be able to demonstrate to them some successes around this, and they are not easy to point to. That would make a big difference.

Senator BOYCE—In the general Australian population you would anticipate that children would move out of home—I have been saying ‘sometime between 18 and 40’—and have their own lives, the lives they choose. We appear not to have that expectation at all in the disability community. I suspect that is because the system has never allowed people to even dream of having that choice. But is it also about the fact that parents or families that have a person with a disability should behave differently? Is it reasonable? Should we be doing something to encourage it? I guess that is what I am asking.

Ms Heggie—I think that those options should be made available to those people with a disability—like your sons and daughters in their 20s—who want to move out and live and be supported in appropriate arrangements. But those options have not been there in the way that some of these parents have wanted them to be. If we were talking about rights and all of that, you would say that, yes, in an ideal world, there should be some right for people with a disability to be supported in alternative arrangements.

These parents have been wonderful in the way that they have given up their lives for this. I am not sure whether those in the younger generation—like my own daughter, who is 28—would be in the same realm as some of these parents in respect of this. But that was the mother’s role, to stay home; they absolutely believed that it was their role in life to support their son or daughter at home for as long as they possibly could. And there are a lot of those people still doing that.

Senator BOYCE—But a lot of that might not just have been about their belief that they should do it; it might have been because they saw no other option—or no acceptable option.

Ms Heggie—’No acceptable option’ would be how I would see it. I do not believe it is a deliberate thing. I think it is that they believe that there are not acceptable options for them out there.

Senator BOYCE—Thank you.

CHAIR—Can I go back to this issue of the assessment tool. We have the ACAT teams that do assessment for aged care—assessing what level of aged care support you are going to get. When we were talking earlier about an assessment tool, is that the sort of tool that you had in mind? Did you have in mind a similar sort of tool, but with different criteria, that looked at what sort of support someone would need when they are ageing with a disability?

Dr Hagiliassis—At the risk of getting quite specific here, our experience in terms of developing tools in other domains has been in utilising existing tools and processes and modifying and adapting them in order to have them capture the needs of people with developmental disability. That would be the approach that I would be advocating here rather than re-inventing a process or an instrument—moreover, looking at how that process or instrument can be adapted to more effectively and accurately capture the needs of the group that we are talking about here today.

CHAIR—We had some discussions earlier in the day—and I think Senator Brown touched on it—about this divide between disability and the aged pension in terms of who takes responsibility. There are the states' disability services, and that goes all down the line, and the federal government's aged care responsibility. If we develop this sort of tool you still have that divide between the states and the federal government about who pays for what. So you would also need those systems to be more joined up, surely. That is also what we are talking about, isn't it?

Dr Hagiliassis—That is true. I think the value of the tool is that it potentially allows you to identify what the issues are for the individual, which can inform the response. In terms of implementing that response, that is another, related question.

Ms Heggie—Just on that issue—you may be aware of it; I think it came about through COAG—of people living in supported accommodation who are retiring and the supported accommodation stating that they could not come back: apparently a policy was approved that the CACPs would enable people to go home. But it has never been implemented. Nobody is too sure about who is doing what. Even though the policy was passed as a way to solve this problem, the whole facilitation process has never actually happened. I wonder if you could resurrect that and have a look at it.

Senator BOYCE—Are you saying that there is funding set aside for CACPs for people in supported accommodation that have not been used?

Ms Heggie—Yes. It has never been instigated. It has never been rolled out. I am just wondering if this committee could go back and have a look at that, please. Perhaps Dr Ken Baker, who is the Chief Executive of NDS would be able to enlighten you in respect of that.

CHAIR—Senator Brown, you were just saying that you thought it had not actually been initiated.

Senator CAROL BROWN—Yes. What did you mean by, 'It's never been rolled out'?

Ms Heggie—My understanding was that it had been approved but there is no process. People have asked about it—

Senator CAROL BROWN—It has never been applied; is that it?

Ms Heggie—That is right. I would be really grateful if that could be looked at because if it was applied it would at least be one piece: there is a nice little solution over here that we could actually—

Senator BOYCE—You have given us some homework now.

CHAIR—We have the departments coming—FaHCSIA and the Department of Health and Ageing. We started with FaHCSIA at the beginning of the enquiry and I have asked them to come back.

Ms Heggie—Well, you could ask them about that.

CHAIR—Exactly, if they do not get there before us and—

Senator BOYCE—I think they are probably listening right now.

CHAIR—If they are they could take that down to pre-empt us asking some questions.

I just want to quickly get back to this issue because it is pre-occupying me to a certain extent—that is, working out how we are going to make disabilities and aged care work better together. We have the review of HACC services and we are definitely going down this line of splitting responsibilities between state and federal governments. It seems to me that that is going to lead us further down the path of separation—not joining aged care and disability. If we are going to get the tool—I am attracted to the concept of the tool—we need the funding to join up as well. Have you thought some more about—

Ms Heggie—You mean disability and ageing funding joining together under one?

CHAIR—Heaven forbid we should have a seamless care approach.

Ms Heggie—That is fine, as long as we call it something else. Also remember, you have got children, a whole lot of other people in this area as well. We do not want the disabled person to all of a sudden be aged at 10. I would caution us to that. Whilst it is a good idea and there may be some real efficiencies and some gains for the total sector, and there certainly are areas of crossover—and one could even argue that the capabilities around the workforce are very similar—there are discrete differences. People who are ageing do have a lot of health issues. People with a disability may not have any. They are people like you and I and they just want to be like that—they want to be mainstream.

Senator CAROL BROWN—I think we are finding that it is not about keeping them separate; it is about there being a gap. The submissions are that it is complex and hard to navigate between the state and federal spheres, and gaps have been identified in funding.

CHAIR—I think this is my third or fourth inquiry where exactly the same issue has come up and we still do not have a solution.

Senator CAROL BROWN—It was in relation to the national hospitals and health reform, where the Commonwealth are looking to take over aged-care funding and HACC, except for here in Victoria and Western Australia.

Ms Heggie—We do not mind where the dollars come from or how they come. Imagine somebody at 67 living in a community based house just down the street being told all of a sudden that they are now going to be Commonwealth funded as opposed to state funded and that there will be a massive re-assessment of their requirements. They are carrying on living there. They should not see any of that. This is a funding issue.

CHAIR—The example we were given this morning from Ms Cooper was that she was moving out of disability support into aged care, and the services she could get under disability were changing under aged care. Because she was a strong advocate, she managed to voice her concern about that. But a lot of people cannot. The point was clearly made to us that people moving out of one system into another were losing the support and services they had had, and they still need those support services. Just because they had turned 67 did not mean that they did not still need those services as a person with a disability.

Ms Heggie—You may want to stay living in your house as you currently are with your current system of support. It should just be seamless; it should continue on.

Senator BOYCE—Another example we have had is not being able to access HACC funding if you are in supported accommodation. Why not? There was also an example of someone moving into a nursing home not being able to keep their funding for mobility aids. They are the sorts of issues that create unnecessary hassles and trauma for people with disabilities and their families. We would hope that we could perhaps start filling those gaps.

Ms Heggie—It is the transition points in people's lives that are so critical and that are not thought through enough. It does not matter whether it is early childhood to school or whatever—those transition points seriously need a rethink.

CHAIR—Yes, there is also the issue of coming out of school and going into employment.

Senator BOYCE—I guess this is the hardest one to get people to think about, because we are talking about death in the end.

CHAIR—Thank you very much. I think you said you were going to send us something extra.

Ms Heggie—Yes.

Proceedings suspended from 2.49 pm to 3.04 pm

JACKSON, Mr Maxwell John, Partner, JacksonRyan Partners

RYAN, Ms Margaret Anne, Partner, JacksonRyan Partners

CHAIR—I welcome representatives from JacksonRyan Partners. 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 15. I would like to invite either or both of you to make an opening statement and then we will ask you some questions.

Ms Ryan—Thank you. Both of us are going to make an opening statement. I have 20 years experience as a family advocate in the disability sector. Particularly, I have worked with families where there is a person with a communication or a decision-making incapacity. I have engaged in public policy and comment over the past 20 years, particularly in disability but also in its linkages to the mental health sector. I have seen planning in the context of its impact on the family and the person with a disability and I do have direct experience with the impact of planning involved in seeking and managing individual support funding on the family and the person with a disability. On a slightly more personal note, my father is 90 and my mother is 87, so I am currently involved in the aged care system as well.

I want to touch briefly on four issues we would like to emphasise for the committee. These are variations in legislation; developments since our May submission, which are around carer legislation and policies; the Allen Consulting report and its recommendations; and adequate resourcing of the potential population and planning. In terms of the variations in legislation, our paper focuses on the policy flow on and service impacts of Victoria’s disability legislation which came in in 2006.

We want to put to the committee that variations in legislation underpin much of the real confusion and ignorance about policy, decision making and programs which surround people with a disability, their families and carers. These variations arise whether it is Victoria compared with the Commonwealth or Victoria compared with other states and territories. No matter how similar the acts may be or how aligned that the legislation regulations may be—and I use the word ‘aligned’ because that is the word that is in the National Disability Agreement—with national policy and reform direction as required by the National Disability Agreement, I cannot emphasise too strongly that, while high level agreement may be reached on the ground with the service providers, in family homes around the nation confusion and ignorance abound.

I think some of the developments since the May submission touch on this. Since the May submission the federal government has passed its Carer Recognition Bill and it has held consultations for the development of the national carer strategy. Almost at the same time, in Victoria in late June, we had a Victorian charter supporting people in care relationships launched. This is further to the 2006 care relationship policy. So at the federal level carers have specific legislation, but carers in Victoria are recognised only within a care relationship policy. This kind of variation between the state and federal governments exacerbates the confusion and ignorance I mentioned above. In August 2010, the 10-year plan for ageing in Victoria was released. Despite the links between ageing and disability, this plan has to date not been promoted in the disability context. They are some of the things which are promoted at a high level but which I believe contribute to what I consider to be a confusion on the ground.

I would also mention the Allen Consulting report. While I expect that you are aware of this report, which is the one that they did about future planning options in the international context, I want to highlight for the committee that recommendations 4 and 5 of this report recommended implementing a planning program similar to the Canadian Planned Lifetime Advocacy Network and in the US *The Future Is Now* program. Those were their recommendations.

There is another thing which I have very strong feelings about. If the committee is going to recommend some form of planning, we submit that this must be accompanied by a realistic assessment of the potential population so that adequate resourcing is made available. I do not just mean in terms of doing a pilot program to see how things work on the ground. In Victoria I obtained customised data from the 2003 ABS survey of disability, ageing and carers. This shows that in Victoria some 20,000 people with a disability aged 30 years and over received assistance from a co-resident parent. About 70 per cent of those had severe and profound disabilities, so you are looking at about 14,000 people there. The 2009 survey—and I believe the results from that will soon start to flow through—will presumably enable similarly customised estimation of potential population so you could have realistic resourcing of any future planning system.

They are the things I wanted to highlight for the committee. I will now hand over to Max.

Mr Jackson—I want to let the committee know that I have had 45 years experience in the disability sector. Principally this included 17 years as a special education teacher in the Victorian education system. I also had nine years as the chief executive officer at Kew Cottages during the 1980s and early 1990s. This was at a time when Kew was a very large institution of some 850 clients and around 900 staff. It was also at a time when there was significant change occurring in the institutional sector across Victoria.

I have also had regional experience in the Department of Human Services. I was principally responsible for disability, which included both the direct operations of the department as well as the non-government sector. I also undertook in the early 1990s on behalf of the government a state-wide review of psychiatric services across the state. More recently, I have had 12 years consultancy experience, significantly again in the disability sector, both in terms of training and development of staff and organisational reviews of funded agencies.

I think it is worthwhile mentioning that, as JacksonRyan Partners, Margaret and I have also undertaken on a regular basis active engagement on policy and legislation that is being pursued by the government in Victoria. We have made submissions and commented on such documents. We believe we have been an active partnership, if you like, in the disability sector.

I would like to make some opening comments, if I may. I want to remind the committee—not that I am sure I have to—that I do acknowledge that the four pillars, if you like, of your task are that you must address the options of people ageing with disabilities and their carers, the issue of quality of life issues and service options. In particular I have a keen focus on what I call the fourth pillar and that is on the other matters that can assist carers to answer the ever-present question of: what will happen when I am gone? I believe that, as a committee in concert with the other three terms of reference, it is particularly important that you keep ever-present in your minds that question that parents ask themselves: what will happen when I am gone?

I remind the committee that in some ways the task that you have been given is not actually new. My history in disability certainly in this state and knowledge across the country is that the issue of planning and the discussion and debate about service options and indeed the concept of quality have been the focus of governments and government departments for nigh on three decades at least. That must raise in our minds the question: why are we here in 2010 asking the question about planning yet again?

In this state we have had 10-year plans since 1986. We have had myriad policy documents coming out from the department. We have had the closure of a number of institutions. Of course, each successive government in this state has been very good at saying how much they have spent and how much more it was than the previous government. Yet, despite all of this, the question in the minds of families—and I might add that JacksonRyan Partners deal a lot with families—is: what will happen when I am gone? So after 30 years of all of this activity we still have not been able to address that question.

For me the significant issue, and the one that I believe ought to be addressed to some degree by the committee, is the question of access to specialist disability services. I believe that underpinning what I see as a pivotal question about access are five key elements. The first one is what I call access and ideology. In Victoria the current so-called new directions place significant emphasis on community inclusion and generic service provision—types of services that we do not disagree with, I might add. However, they are emphasised almost to the exclusion of specialist disability services, and specialist disability services have been confined to services of what I would call last resort. In my way of thinking, this is unadulterated nonsense. It is driven by ideological purity and it fails to take account of the concepts—much flaunted by governments these days—of choice and self-direction and the significant one of individual needs.

The second pivotal matter underpinning this question that parents ask themselves about access is—Margaret has already touched on it—the legislative frameworks. To my knowledge, there is no legislation in this country that identifies service access as a right. This is despite the fanfare about rights since the early 1980s. It is also despite the fact that in other jurisdictions the concept of rights is enshrined in legislation, whether it is about pensions or access to particular types of services such as education.

The third element that I believe is a component of this access to disability services is what I call the access rules. Within Victoria, if the committee were to look at Victoria’s policy on service access, you would find that in fact it is an exclusionary policy. It excludes and diverts people from the specialist disability service system despite the fact of people, through their planning, identifying those service needs—that is, the specialist service needs—as the ones they want.

The fourth element, which of course is enshrined in legislation in this state, is the concept of priority of access. It is almost like drafting sheep: ‘You’re in; you’re out.’ Who is the priority? Again, this is despite the fact of pursuing this concept of needs, rights and choice.

The fifth one is, in fact, confining people to a waiting list—and I deliberately use the term ‘waiting list’. In Victoria, the government and the department have quite successfully established or coined the phrase ‘Disability Support Register’, or DSR. Let us not be fooled by the terminology. The language of disability over recent decades has been a language that has avoided reality. These are waiting lists and, even though people might have planning established for them, the fact is that they are confined to the waiting pen to see if they get a service or not. They are diverted from the specialist disability service. I therefore believe that, unless your committee addresses and confronts this issue of access to services as a legislated right, the issue of planning will simply be a nonsense.

Senator BOYCE—I just want to start out by asking about this: you have described JacksonRyan Partners as a boutique business unit. Can you give me some idea of the business activities that you do undertake?

Mr Jackson—I will introduce that matter. JacksonRyan Partners have been operating for just over 12 months, although Margaret and I have been doing work in the disability field over the last five years. We have a range of business activities. We work a lot in the area of conflict resolution; formal grievance hearings in various government departments; mediation and facilitated discussions; and investigations—which includes investigations in the disability sector, such as allegations of abuse against clients or misuse of client funds. We also do organisational reviews specifically in the disability sector, and we assist disability agencies with funding applications to government departments and developing new directions for their services and planning for the future. So it is a mixed bag of services.

Senator BOYCE—What area would the majority of your clients come from: the service provider area or what?

Mr Jackson—Principally the funded non-government sector but increasingly—and Margaret can make a comment on this—we are establishing a client group of families. Margaret has greater expertise in the area of individual planning than I do and we are starting to have families make contact with us.

Ms Ryan—That is something I was involved in on a paid basis before we became JacksonRyan Partners. Also we recently obtained a consultancy with a group of families who are looking to set up an accommodation facility and that will be paid. We also present at conferences talking about how the system works, and that has been well received by families. We have also done some paid training with families on how the system works. One thing that was really nice is that we recently had an 85-year-old mother tell us it was the best session she had ever been to. We think that over the years she had been to quite a few.

Senator BOYCE—We have had lots of evidence about the confusion, not knowing what is out there, not knowing how to find out what is out there, finding what is out there but then finding that there is a waiting list of 20 years or something for it, or whatever. You are trying to address that with individual families and with groups of families, are you?

Ms Ryan—Correct.

Mr Jackson—And funded agencies.

Ms Ryan—I also believe there is a lot of confusion among funded agencies as to how things work.

Mr Jackson—Just an example, if I can take half a minute. This year, for example, we concluded a major assignment on behalf of a funded agency which had raised $1.2 million to build a seven-bedroom support accommodation facility and they were having no luck with the state government department responsible for it—

Senator BOYCE—Because of congregate care, so to speak.

Mr Jackson—Exactly. They engaged us to negotiate with the department and in a way take the department on. We looked at various funding models, which included the individual support packages, and the agency has in fact been successful. I raise this as an example because here is a situation, it was a Greek agency where they had raised every single dollar of that $1.2 million, purchased the block of land, they were ready to go, they had families who were desperate for supported accommodation for their family member, and still the government department refused to engage them, to the point where Martin Ferguson, who is one of your federal colleagues, came down and we got him to speak. We had various state members of parliament from all sides of politics engaged. Margaret and I had to become registered lobbyists, otherwise the department would not speak to us.

Senator BOYCE—So in fact you broke several rules there. Not only was it congregate care but also congregate ethnic care.

Mr Jackson—Yes. The important thing is that six people who were in their 30s and 40s and had been living at home with their mums and dads where their mums and dads were now approaching 60 and 70 and 80 and were no longer able to adequately care for them were given an appropriate home and relief from their mums and dads and the family unit still retained the sense of family.

Senator BOYCE—I might follow on from that. One part of evidence that perhaps has not come out as clearly as it might is all the options that families are currently looking at in terms of accommodation, which is a big one, but also other ways of going about getting to the stage of answering the question of what happens when I can no longer care. Can you run through, from your experience, Ms Ryan, the sorts of options that families and services might be considering in terms of accommodation?

Ms Ryan—I think the options which families I know about have looked at are fairly well known. There are the ones who are looking at a circle of support. They have that particular kind of support from the family or from friends that they believe they can set in place a network of people who would take care, though care is not the right word perhaps, not terribly politically correct, but support—

Senator BOYCE—Someone use the term earlier today of caring about and caring for. The caring about was what the circle did.

Ms Ryan—That is one bit, and also that same terminology is often used—you hear parents say they want this for siblings, to care about, not to care for. That to me comes across as one of the things that the parents do not want, that they do not want the siblings, if there are siblings, to have to take on the same kind of caring role that they have had.

Others are looking at some kind of mixed community, an intentional community that they would like to set up for their sons and daughters. It would stay in the local area and have some kind of ongoing management or be auspiced by another organisation that they feel comfortable with. So they would stay linked into where they have been living. Others we know about—a family in particular where there are three, I think, adult children, sons and daughters, with disabilities—are looking to leave the house to an organisation that would take up the care and support of the people who would live in that family home, and eventually it would become an asset for the organisation. That is another way they are doing it. There are a whole myriad of things out there.

On the other one we have seen, which is very attractive, there is Jewish Care in Glen Eira Villas. I do not know whether you get a chance to do site visits, but it is in Glen Eira Road, Caulfield. There are four villa units and four bed-sitter rooms in each villa. There is a large kitchen-family room, a combined area, for people to live but everyone has their own bed-sitting room and their own bathroom. Those people do not require 24-hour staff support but there are staff on site during the day, and there is one person who looks after the interests of those 16 people, doing all the administration for them. That is the other kind of model that has appealed to families. There are a whole range of things.

Basically families want somewhere where their sons and daughters are going to be safe and secure and where there is someone—an organisation or people—who provides 24-hour supervision. Those are the broad parameters I would put it in. There are some families where it is incredibly difficult, because a lot of it comes down to finance, what they can afford, because the person with a disability is a pensioner and possibly has not had an opportunity to go out to work or does not have the capacity to work. I do not think there is any one model.

Senator BOYCE—No, absolutely. The villa model you are talking about sounds quite similar to something that has been done in Townsville recently. The question that lies at the bottom of all this is how to make those solutions sustainable in the absence of the parents or the family who are the ones who have driven the monitoring and the quality control all their lives.

Ms Ryan—I do not know whether you can ever actually replace parents. If I pick up on the aged cohort on a personal basis, my 90-year-old father and 87-year-old mother would of course love to stay in their own unit—they are now in a retirement unit—but they realise that they are probably going to have to go into something that provides much more care for them, because they just do not have the physical and mental capacity now. They can see that happening. It is not something they want to do but they are gradually having to relinquish things more and more to other people. That is perhaps the hardest part: the handing over to other people. The organisations are there that have the funding, if they choose to use them, and they can safely leave their sons and daughters in the care of those people.

Senator BOYCE—And the organisation will continue?

Ms Ryan—I think they are fairly realistic. They hope the organisation will continue but there is some kind of structure there. Continuity of care is a big thing for families—continuity of care of people coming into their homes. Again, this is one thing for families of those who have been involved in the system. As I said, my family has been involved for 20 years now with a number of people coming through the house, and if you get a carer who stays around for a few years you consider yourself lucky.

Senator BOYCE—Someone was giving evidence this morning about having services provided by seven different organisations to put together a sufficient package to meet her needs. That would be fairly amazing.

Senator FURNER—Since the induction of the Disability Act 2006, how has that changed things? You raised the concern about ‘What will happen when I’m gone?’ Regarding all the other cultures that may have been in place prior to that, has that been satisfied in terms of planning since the act was put in place?

Ms Ryan—One of the things that is very unfortunate about the Disability Act in Victoria is that it is deliberately about the person with a disability. Even though this act covers children as well, family carers are very much sidelined. There is the emphasis on the person with a disability. The other thing that is happening in Victoria at the moment is they looking at the Guardianship and Administration Act. This is an ongoing concern for people: who makes the decisions? There is an emphasis on things being person-centred. I have no problem with that—I really do not. The theory of it is something that I strongly support. But if the person with the disability is someone who lacks decision-making capacity or communication capacity, who makes the decisions and who becomes their nominated person, or whatever you want to call them? That is where the really hard issues arise. On the Disability Act in Victoria and the emphasis on planning, what I was trying to get across in the paper was that, although you have a right to assistance with planning, the right does not mean very much on the ground.

Senator FURNER—In terms of the government’s decision to not sign up with HACC, what has that done to service programs in the state?

Ms Ryan—I do not think the effect of that has started to be felt yet. I think there will be much more as it starts to happen in other states. Maybe there will be service reconfiguration. I really do not know. It will be much more around the planning of services. My understanding is that HACC currently would provide services to people with disabilities—I could be wrong here—who have less need in terms of the hours of care that they need in the home. The Scope people mentioned that people at HACC do not do PEG feeding. I was really hopeful that HACC in Victoria would come under the National Disability Agreement so that maybe some of the lines of authority would be much clearer. To me, while we have the split between the health department and Health and Ageing—in Victoria it is community services—the lines of authority make things very difficult.

Senator FURNER—You made some comment in your submission about the FaHCSIA booklet *Planning for the future: people with disability*. Are there any areas in that that you would like to comment on—in particular about making improvements to the booklet?

Ms Ryan—No. That booklet just highlights the range of issues that families have to consider. It is a huge ask.

Senator BOYCE—It is great for about five per cent of the community.

Ms Ryan—You need to ask yourself: why do we ask families with a person with a disability to do that kind of planning and yet we do not have the same kind of booklet for families where there is no person with a disability? It is terribly discriminatory to put the onus on the parents and the families all the time to do this and to provide the services. My experience is that, broadly, families can say what the needs are for the person with a disability. To what extent do they really have to go to self-provide or be the drivers for the service provision for their sons and daughters with profound and severe disabilities? That is where it becomes difficult for me: when you know the strains and stresses on families for 10, 20, 30 or more years, and we are now asking them to do this planning. We are also asking them to do planning for things which do not exist. It is really insulting to families when you ask them to do that. I do not think it is because families are incapable. I believe that, in terms of the work that we do, we approach it fairly simply. The person with a disability, in most cases, is an adult person on a disability support pension. If you start on that basis and work out what can be done, you start to get more realistic about what life is.

Mr Jackson—Senator, if I can just come back to your question about the legislation, one of the things that we believe happens in Victoria regarding legislation is often the failure of government policy or departmental policy procedures to enact the letter and the intent of the legislation. As an example, I think it is section 50 of the disability legislation in Victoria that talks about access as a fairness and equity exercise, and yet any one of 140 funded agencies across the state and any one of eight DHS regions can be the determiner of who gets access. We met with senior departmental officials to thrash out this question of fairness and equity and asked them how they could define it and determine it. That was in February. We have met with them twice, and we still do not have an answer. The reality is that they cannot answer the question. So we have to be very cautious. We can have the best legislation but, unless legislation is enacted through policy and procedures to the intent of the legislation, it can be diverted.

Senator FURNER—Thanks.

Senator CAROL BROWN—I will stay on the national health and hospitals reform. You have noted about the HACC services. On the Victorian government not signing up with the HACC service part of the national health reforms: what impact on that service in Victoria do you think that will have?

Ms Ryan—My understanding of that, the best that I could ascertain, was that one of the unions that is involved in the delivery of services or covers the workers who are involved in the delivery of services was very instrumental in Victoria keeping HACC outside the National Disability Agreement. It ran the argument, and I believe it supported it quite well, that to take HACC outside would mean a decrease in wages and terms and conditions of employment for people, and they equated that with the quality of care that people got. Certainly there was no consultation held—to my understanding—with people in the disability field as to whether or not putting HACC services into disability was a good thing. But, again, I am not even sure that there are that many people who are actual service users who understand that HACC services are a different service system to disability funded services and that there is different legislation.

Senator CAROL BROWN—But you do not have a comment on the costs or the benefits of being part of it?

Ms Ryan—I got excited when I thought that HACC was going to come under the National Disability Agreement because, when the National Disability Agreement was signed, which is almost two years ago, I thought that the reform directions there and the things that were being spelt out about population planning and unmet needs were real advances. I am terribly disappointed that, two years down the track, we do not seem to have got to the stage of really implementing very much of what is in there. I got excited when I thought that HACC would come under it, because, again, it is these lines of authority and where things are. Even in terms of the health and hospitals agreement, which I did follow through, I got excited. If the federal government was not going to take over disability services and take full responsibility for them and reverse the roles, not necessarily a service provider but becoming much more the driver of policy and how things are implemented across the nation, under 65/over 65 was something that people could understand—that is, if you are under 65 you are a state responsibility; if you are 65 and over you are a federal responsibility.

I know that people in group homes are an issue, but to me there are not so many of them. We only have about 4,700 people in total in group homes. There are about 5,000 in disability residential care in Victoria. I know they have got the numbers, but it is a bit difficult to get questions on notice answered and to get good data now—or it has been. But I just do not think there are so many of them who have had lifelong disabilities. I think that that kind of split can be a really good thing. That is my personal opinion, but I do not know what you do. There are always going to be people who, to me, use the Commonwealth-state split as an excuse not to do things. Often it comes down to money, so what do you do about that? I do not know.

Senator CAROL BROWN—Has JacksonRyan put in a submission to the Productivity Commission inquiry into disability?

Ms Ryan—Yes, we have. We made an initial submission. I think it was something that we had already done, but we have put a submission into that and we have been following it quite carefully. But we also made the decision that we would wait and see on the first draft report and concentrate efforts on that.

Senator CAROL BROWN—Did you make recommendations in your submission to that?

Ms Ryan—No, not really.

Senator CAROL BROWN—Thank you.

CHAIR—Senator Furner, do you have any more questions?

Senator FURNER—No.

CHAIR—Senator Boyce?

Senator BOYCE—Yes. If we could just go back to the point about the state disability services act having provision to give people the right to assistance with planning: if I ring disability services and say, ‘Please give me some assistance with planning,’ what is going to happen? What is the practical experience?

Ms Ryan—It depends what region you are in. There are eight regions, and each region has a different experience. Even in Victoria, that is what happens. But you will no doubt go on a waiting list. The department’s last annual report put it at about seven weeks for intake and response. My experience has been that it is much longer than that.

Senator BOYCE—And then what do I get?

Ms Ryan—Then you will get a person—they might be called a case manager. Depending on what region you are in, it could be someone who works for the department, or they have also contracted two outside agencies to provide planning services.

Senator BOYCE—Can you tell me what those agencies are?

Ms Ryan—I do not know their names at this point in time.

Senator BOYCE—If you could perhaps give them to me on notice, that would be good.

Ms Ryan—Yes, I could find out for you. They have a dual system—whether it is complex planning that is needed or fairly simple planning that is needed.

Senator BOYCE—And is this about lifelong planning or just about how to spend your package?

Ms Ryan—Well, you can ask for it at any time. You can ask for it before you get a package, but to get a package, to go on the register, you have to have a plan done.

Senator BOYCE—But that is really a package plan; it is not about what is going to happen when I can no longer care, is it?

Ms Ryan—No—

Senator BOYCE—No, exactly.

Ms Ryan—it is up to you; it is up to the family or the person with a disability what kind of plan they want to do. They can do a whole-of-life plan, but to get a package you will only get funded for things that you need now, because to go onto the Disability Support Register it can only be things which you have a current need for.

Mr Jackson—Our experience tells us that families are often reluctant to identify the full ongoing and long-term needs of their family member with a disability. Margaret has presented at a couple of conferences this year across the state to emphasise the importance of identifying all of the needs and letting someone else make the decision of whether you get the money for them or not. One of the things we do when we work with families, too, is to really emphasise that point: what do you actually need on a minute-by-minute, day-by-day, month-by-month time frame over years and years and years? It is very difficult to determine, but families by nature are reluctant to express that.

Ms Ryan—If I could just follow on from that, one of the things that we have said to families is, ‘If you don’t identify your needs, no-one else is going to.’ But the other cute thing—I will say it is a cute thing—that the department do is that they will only accept needs, when you have a funding package, of the amount that is allocated. They do not want their system to know about any unmet needs that you have.

Senator BOYCE—So when we are talking about the unmet needs quantum—and we know that there are people on waiting lists and we know that there are people who could not be bothered getting on the waiting list because the waiting list is so long—there are also people who are funded who have unmet needs of reasonable capacity?

Ms Ryan—Absolutely. What we say to them is: ‘You might have a funding package but you now have to do an application to go on the register for your unmet needs.’ But because they have a package they will sit there. To give you an indication, the figures that came out in June for Victoria’s disability support register, or their waiting list, showed that there were only around 2,600 or 2,700 people on that. Given that there are some 14,000 people with severe and profound disability living with their parents—let alone those who might have some kind of independent living but their parents are doing all the supervising and things like that—we know that there is a huge cohort out there who are not tapped into the system.

Mr Jackson—It is probably worth commenting that it is our experience, from working with families, that families now are almost like a small business. If their son or daughter has an individual support package, if they are required to do this planning, whether it is with support or without support and then to follow it up and then with the unmet need to have another go, it is like running a small business. I often think that government officials in particular have no idea of the stresses and strains these so-called new developments and new directions in disability place on families who are already under the enormous stress and strain of dealing with and supporting their family member.

Senator BOYCE—Are you aware of microboards? Could you perhaps describe for the benefit of *Hansard* what a microboard is and what your experience of them is.

Ms Ryan—I know I am nodding my head to say that I am aware of them, but it is mainly through reading about them. Families are setting up structures around the person with the disability to ensure that there is some kind of support system in place when the parents are no longer around to do the work. A lot of it comes down to time, interest and capacity of families to do this. As Max said, much of it is like running a small business. So many of the families I deal with are just so tired and worn out and the person has such high support needs, and to get involved in that kind of organisation really is a big ask. But, at the same time, I think it is fantastic that there are families who are out there doing that.

Mr Jackson—There are any number of families who are willing to bond together to self-support. But, again, our experience is that government departments are very good at road-blocking and putting up barriers to families. We are involved in a group at the moment, as Margaret indicated earlier, looking at some planning developments for a residential setting. I take the view that if families are prepared to put in their own money and take the initiative, the government should assist them. They should help them rather than road-block them. The road blocks are often based on ideology.

We still have government officials and so-called advocates in this state wanting to re-run the history of deinstitutionalisation. That is a dead issue—it died in 1986; let’s get on with life. They use it as a rationale, if you like, of why you cannot have congregate care or small group living. Walking up the street today you can see any number of apartment blocks around here and gated communities throughout Melbourne for the elderly. They are acceptable, but they are not acceptable in the disability field. It is utter nonsense.

Ms Ryan—The Victorian government actually gazetted a new institution—and I will provide you with the information on it. Albeit, it is very small scale, but they actually gazetted it. Even though, when they had the legislation committee for the Disability Act, it was black and white that there will be no institutions in Victoria, there has been an institution gazetted.

Senator CAROL BROWN—What do you mean by ‘small scale’?

Ms Ryan—It is two houses—so for about 10 people.

CHAIR—Thank you very much for your time and your submissions. It is very much appreciated.

[3.50 pm]

TREGALE, Mr Anthony David (Tony), Coordinator, Secretary and Public Officer, Lifestyle in Supported Accommodation Inc.

CHAIR—Welcome. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you.

Mr Tregale—Yes.

CHAIR—We have your submission; it is No. 78. I invite to you make an opening statement and then we will ask you some questions.

Mr Tregale—Thank you. I am not sure that I can follow the last act! LISA is a small parent support and lobby group, and all its members have similar concerns. The mission statement of the organisation is the provision of quality life care for people with an intellectual or multiple disability who live in supported accommodation and whose families need support to be carers for as long as they wish to be and in the knowledge that their family member with a disability will have the right to a quality of life care, accommodation and support package whenever they choose.

The objects, activities and statement of purpose of Lifestyle in Supported Accommodation Inc. is to empower and support families with a member who is living in supported accommodation to better understand service provision procedures, care policies, standards and values and, thereby, be better positioned to scrutinise service providers. The overall problem for people with a disability and their families with getting appropriate support and that support providing them with quality of life care is that it is complex per se but made more so by unnecessary bureaucratic processes.

Nevertheless, I refer to the main focus of your mission statement, which is that of people ageing with a disability. Given that most people with an intellectual or with multiple disabilities have limited intellectual capacity, their existing capacity will naturally deteriorate with increasing age. Their deterioration will be compounded where they have received little active support—that is, interactive developmental and social activities in their younger years, especially. Research shows that those with high support needs who receive intensive intellectual developmental activities in their early years in the form of, for example, ABA, followed by consistent interactive developmental and social activities in later years are better equipped to face the world in general and ageing especially.

Although special developmental schools now generally do very well in providing their students with many skills, these skills are frequently dropped like a brick when these students move from school at around the age of 18 to a day activity centre, where DHS in Victoria rather than the education department are the supporters. Activity skills and social interaction can drop further where the now adult person starts living in a DHS supported accommodation group home for whatever reason.

The Department of Human Services here in Victoria produce very good, very comprehensive and well-documented care policies, standards and values for services to people with an intellectual or multiple disability. I draw your attention to the manuals of the department—I have them here—which are absolutely superb. There is no doubt they have very good policies that are well documented. The problem is that these policies, standards and values are not fully implemented at the service points within their direction, intention and spirit for the direct benefit of those for whom they are intended: people with intellectual or multiple disabilities—the residents of DHS supported accommodation group homes. Frequently, many high-support needs residents get little more than basic minder care, whereas the department's care policies, standards and values clearly state residents should receive quality of life care, this being interactive, developmental and social activities, commonly known as active support.

Care policies, standards and values are not consistently implemented mostly as a direct result of the failure of DHS management above the level of house supervisor to properly manage the business of providing care to residents which is within the direction, intention and spirit of departmental care policies, standards and values. The reason DHS management fail is a complex puzzle of traditional Public Service culture. Most Public Service staff see themselves as having safe employment, with few expectations set, monitored or maintained such that they shall provide care within department care policies, standards and values. One of the core problems is that the DHS Public Service captive market management do not see a way through the entrenched and traditional Public Service culture to manage direct-care staff.

When we were lobbying the DHS for quality of life care in contrast to minder care for our son, the department told us that we did not know what we were talking about. In consequence of this, my wife, Heather, did 12 months full-time TAFE, got her ACRACS, as it was then—it is now certificate IV—and worked in direct care for four years, not for the money but like a police officer undercover. She said, 'I'll see what happens behind those closed doors.' She saw firsthand the questionable activities going on behind closed doors. We have an attachment showing that to leave with the committee.

Good staff are frequently dragged down or leave as DHS fail to properly manage their services. Residents rely on the integrity of staff—there is nothing wrong with integrity if it is good integrity—rather than on the direction of management to ensure that the care is within departmental care policies, standards and values. Many staff stay casually employed to keep out of the politics. We cannot blame them for that, as some houses are shocking for staff politics. It is difficult to get across to the department that there are huge problems, because they always say they need documentation and reports about everything and, when you do present that evidence, they say it is not good enough or the issue is perceived by the person reporting it. It is a cat and mouse game all the time. Casuals will not report questionable activities because they will not get any more work. The department do not like whistleblowers. DHS frequently say that complaints from families are just their opinions or views, implying that families do not know what they are talking about. They apply this philosophy even where families are quoting from DHS policy.

DHS management above the level of house supervisor do not proactively evaluate staff performance but rely on complaints from other staff, residents and families. Families lack support in Australia, as it is mainly 'do it yourself'. Social services in Australia are poor in comparison with the UK, for example. In the UK, social workers do the legwork rather than, as here, just referring parents to this or that so that parents have to run around looking for this and that and there is no support for them.

At DHS job interviews, applicants need to know what DHS want to hear—that you will be a good public servant—whereas in outside industry they want to hear your potential. DHS refuse to meet with us to discuss why, for example, on one occasion we had very good services. We said, ‘Why don’t you look at it and emulate it?’ They do not want to know.

Casual staff are not directed, as the lady who spoke earlier said. She said: ‘I don’t know what to do in the house with the casual staff in the house. I don’t know what to do. I think I’ll go and make a cake because I don’t know what to do.’ What she should have been doing is interaction and developmental and social activities with the residents rather than just standing around. Smear campaigns are favourite weapons of the DHS management against families who dare to question service level and quality. The DHS has a captive market, as did Telecom before Telstra. There is no reason for customers or customer service.

In conclusion, over the years we have proven that the level and quality of care is mainly due to attitude of management and staff rather than funding level. Today we have heard all about how much more funding we want. Let us ensure that, where the funding is given, there are plenty of expectations set, monitored and maintained.

Senator BOYCE—How long has LISA existed?

Mr Tregale—In an incorporated form, about two years.

Senator BOYCE—What prompted you to establish LISA?

Mr Tregale—Because so many of the parents involved with LISA were getting what we call the royal run-around: the cat-and-mouse game with the department. They were complaining, but their complaints were not getting anywhere. So we changed from an individual basis. We used to chase individual complaints; the families chased individual complaints like, ‘This was wrong,’ or, ‘That was wrong.’ We have now changed the policy towards systemic problems, because it is the systemic management which seems to cause the individual problems to occur in a revolving door.

Senator BOYCE—Were you a group of parents associated with one particular service provider initially, or what?

Mr Tregale—Only the DHS is a service provider.

Senator BOYCE—You have explained that you are there to help families and prepare and educate them to undertake advocacy, basically. How do you do that? What do you do?

Mr Tregale—We help them understand. When they have been told, ‘This is not right’—what they are saying—or, ‘This is not right,’ we can check out the manuals and find out. People do not quite understand all of it because it is very complex in here to understand the rights and entitlements of their family members and themselves. Quite often people do not write a letter in a certain way; they do not write it in the best way to approach a government department. So we are quite happy to do that for them as well.

Senator BOYCE—Do you help families on a case-by-case basis, or do you run workshops, or both, or what?

Mr Tregale—No workshops. It is just case by case.

Senator BOYCE—You have made the comment here—and I was really interested to see your comment:

… group homes in the community are HOSTELS not HOMES!

And you talked about some of the reasons why that is the case. What does DHS say when you bring those issues to their attention?

Mr Tregale—They generally do not want to know.

Senator BOYCE—You have mentioned that direct care staff cannot be moved from a particular group home if they do not want to be moved out of it. Are you able to give us any examples of that—without names?

Mr Tregale—Where parents say that this person is—we had one particularly good example from the group home our son was in previously and the person would not go anywhere near the residence, not at all. He used to spend his time cleaning shelves in the kitchen. He would do anything to pass the time between the shift. He would not go anywhere near the residence. A lot are like that. They are worried about catching a disease off someone. They wear gloves. The department will say that is because you pass something on from one to another. These people do not have a disease; they just have an intellectual disability and some people think that these are terrible people we have to keep away from. So the interaction is limited.

Senator BOYCE—I imagine there is some overlap with workplace health and safety or the way staff behave because of workplace health and safety instructions, which stops the behaviour of helping towards the creation of a home-like atmosphere.

Mr Tregale—Yes, very much so. It is very much a staff workplace, more than a home.

Senator FURNER—I asked Scope, a previous witness, about the figure in their submission of $2,000 per month for accommodation. In your experience with LISA, what would be the average rate?

Mr Tregale—In DHS?

Senator FURNER—in DHS, yes.

Mr Tregale—They keep it very covert. The department is very secretive about this sort of thing.

Senator FURNER—But you must have an idea yourself.

Mr Tregale—We do, certainly. I have none recorded per month but the figure in here is about $130,000 a year.

Senator FURNER—That would be the average figure?

Mr Tregale—These are just figures that we hear roundabout—

Senator BOYCE—Is that the cost—but you would not pay that.

Mr Tregale—Sorry—I am not sure which figure you—

Senator FURNER—What would you pay for accommodation?

Mr Tregale—The figure you pay per month: sorry, you are talking about the three components—rent, housekeeping and personal expenditure.

Senator FURNER—What would you pay for rent?

Mr Tregale—I could not give you the figure off the top of my head. We do know exact figures because we are plenary guardians and administrators. My wife deals mainly with the administration side, so I could give you the exact figure but not off the top of my head at the moment. The thing I was talking about before was support for the staff because the biggest component is staff. That is why you hear a lot of people say, ‘Can we get families to run a house?’ For example, if I were to give our house to the system and say we will have our son plus a few others living in that house and we give them the house, we know of times when the department has turned that offer down. They said, ‘We don’t want your house,’ because it costs them too much in staff. They are concerned about the cost of staff—we are talking about $130,000—that is what they are worried about. The figure you are talking about, I could certainly send you the exact figure.

Senator FURNER—On notice, if you could do that.

Mr Tregale—But I am sorry, I do not have that off the top of my head.

Senator CAROL BROWN—In you submission you say that one of the major factors which limit people with a disability in their families planning for the future is the present handout services. I am sorry if you have already explained, but can you explain that to the committee?

Mr Tregale—I think the last figure was separate from a few others because there is no entitlement to a service. What we call a handout is general government revenue.

The money, as far as we are concerned, is coming from general government revenue. So we consider that as a handout and not an entitlement. The NDIS is going to be, hopefully, a percentage of the Medicare levy, which means everyone will pay, and if you are paying for something it is not a handout, it is an entitlement.

Senator CAROL BROWN—Then you go on to say that there is little reason to value customers or concerns, or provide meaningful customer service.

Mr Tregale—If it is a handout, yes. If you are paying for something you have more of a right to it than if it is a handout.

Senator CAROL BROWN—Obviously you have had some experience where you believe that the customer or the consumer is not being valued by these providers. Is that what you are saying?

Mr Tregale—All the parents in the LISA groups have had that experience, yes. There is no entitlement to any of the rights in here. In fact, our behaviour support plans are quite thick documents and are the standard for most people. For our son, it was an excellent document. We had to finetune it a little bit but they captured Paul really well. We were really surprised, although I am not surprised really as they do that for everyone. We just had to do a little finetuning on it. It is a really good document, but most of it does not get implemented. We are saying that, if we were paying for this service, we would then have more right to say, ‘Hang on, we’re paying you, how about you fix that, otherwise we’re going to go somewhere else.’ We have no choice of service providers. If we had a choice of service providers we could say, ‘You’re not implementing this policy. We will go to another service provider.’ That is why we saying there should be choice. I think the last speaker said that as well that there should be choice. The choice is what brings up the quality of care in our opinion.

Senator CAROL BROWN—I take it from your comment that LISA has provided a submission to the Productivity Commission into disability?

Mr Tregale—Yes, we did.

Senator BOYCE—You talk in your submission about families wanting assurance that their family member with a disability will receive quality of life care for the rest of their lives, and this inquiry is about that sort of lifelong planning for what happens when the parent or carer can no longer care. You talk about an independent complaints process and a more effective service inspection process. Could you explain both of those a bit more and any other thoughts you have there that would try to ensure the quality of life for the person with the disability?

Mr Tregale—Certainly the inspection side of it—I think that was mentioned earlier today as well—such as community visitors, which I think acts in most states; it is certainly at least in New South Wales as well as in Victoria. We were community visitors when the act came in first here in Victoria. We did about six years as community visitors. At that time the community visitor legislation, as far as we were concerned and as most people across Australia were concerned because we had heard a few more comments, said that what we had in Victoria was excellent. We found it very good when we were doing community visitors at that time. Since this new act came in in 2006 community visitors and the act of community visitors were watered down quite a lot. We are not community visitors anymore. We had a cause to ask them whether they could help us with some care problems and so on for our son. It is very hard to get them to do very much. In fact one of the classics with community visitors is that, when we were having major concerns with the quality of life care of our son, we said, ‘What are community visitors saying about the home?’ They said, ‘They give us a clean bill of health.’ I said that you have to be joking. How can they do that when we have that many complaints? We would like to see the community visitor who visits us and talk to them because we do not think they are seeing the right picture. They are seeing some different picture than we are seeing. They would not let us do that. The Office of the Public Advocate refused to allow us to meet with the community visitor. They basically still are doing that.

Senator BOYCE—That was a person?

Mr Tregale—I am sorry, I have forgotten the first part of your question.

Senator BOYCE—The first part was around an independent complaints process.

Mr Tregale—For the independent complaints process, one of the things we have been on about for a quite a long time is a complaints process. When Cheryl Garbutt was the minister here we went to see her at a meeting and one of the things we brought up was this and she said, ‘You’re talking about that but what is really happening is you’re just public servants checking on public servants.’ Some time after that they brought in—whether it was partly because of that, I do not know—the ODSC, the Office of Disability Services Commissioner, in Victoria, which is a complaints process, which I am sure you are all aware of. We must have put in something like about 10 complaints since they started and I do not think one of those complaints has ever got anywhere. One of the things they say is that it is an independent statutory body, a pseudo government department, or as Maggie Thatcher used to call it, a quango. We do not see a pseudo government department questioning a government department to any great extent. We would like to see a complaints process where the people on the panel are from outside industry, such as BHP, Coles, Myer, David Jones et cetera. Our eldest son is a corporate business manager and he says that it does not matter whether you manage a steel mill or a bread company, it is the same management. We feel that those companies would be quite happy to put someone on the panel pro bono—a manager or director—and sit on the panel to have a truly level playing field and even have a level playing field for parents.

Senator BOYCE—To assess complaints. Who appoints the current commissioners? Are they appointed by the minister or is it a more independent body?

Mr Tregale—I think so, but I cannot be sure of that.

CHAIR—Thank you very much for your submission and evidence today.

Committee adjourned at 4.18 pm