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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

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

MONDAY, 8 NOVEMBER 2010

CANBERRA

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SENATE COMMUNITY AFFAIRS
REFERENCES COMMITTEE
Monday, 8 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, 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, 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

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

ROSE, Ms Sharon, Acting Group Manager, Disability and Carers, Department of Families, Housing, Community Services and Indigenous Affairs

WALSH, Ms Donna, Assistant Section Manager, Disability and Carers Payments, Department of Families, Housing, Community Services and Indigenous Affairs

WINKLER, Ms Deborah, Mental Health and Autism Branch Manager, Department of Families, Housing, Community Services and Indigenous Affairs

CHAIR (Senator Siewert)—Today the Community Affairs References Committee commences its public hearings for its inquiry into planning options for people ageing with a disability. I welcome officers from the Department of Families, Housing, Community Services and Indigenous Affairs. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you and I know you are all fully familiar with it anyway. As departmental officers you will not be asked to give opinions on matters of policy although this does not preclude questions asking for explanations of policy or factual questions about when and how policies were adopted. The committee has before it your submission No. 20. I now invite you to make any opening statements you would like to make and then we will ask you some questions.

Ms Bedford—We welcome this inquiry into planning options for people ageing with a disability and carers for people with a disability. We note the new terms of reference and the focus on options for and services to assist people with a disability and their carers to plan for the long-term future. It is key that options and services are appropriate, effective and available for carers wanting to pursue future planning. As such it is important to provide details about those initiatives that are currently in place or under development and how initiatives will increase service delivery options for people with disability and their carers and therefore increase future planning options in the short and longer term.

Recent work by the Australian government to develop the National Disability Agreement, the draft national disability strategy and the national carers strategy about which we are currently consulting has considered the need for people with disability who are ageing and their carers to plan for the future. These initiatives have been informed by the Australian government’s ratification of the UN Convention on the Rights of Persons with Disabilities and the optional protocol to the convention. As part of the national disability strategy the government has asked the Productivity Commission to conduct an independent inquiry into the costs, benefits and feasibility of a national long-term care and support scheme for people with disability. The inquiry will examine whether a long-term care and support scheme is appropriate for Australia. This includes extensive modelling and analysis of interactions with existing service systems.

The appointment of the Productivity Commission recognises that this is a complex area which directly impacts on people with disability and their families in Australia. It will consider costs, implementation, design issues, governance arrangements and administrative issues including for a social insurance model that reflects a shared risk of disability across the population. The recommendations from the inquiry into long-term care and support will guide future Australian government policy for people with disability and their carers. The inquiry is seen as an initial step to build an evidence base required for the government to consider future reform.

The work of the Australian government to support future planning options and services for people with a disability who are ageing is formed through consultations and inquiries that have been held over recent years. The committee would be very aware of these and has been involved in a number of them. They include the Senate Standing Committee on Community Affairs report on the funding and operation of the CSTDA, the Senate standing committee report on special disability trusts, the 2009 national disability strategy consultation report *Shut out,* the April 2009 *Who cares ...*? report of the inquiry into better support for carers, the February 2009 pension review report, the 2009 report of the Disability Investment Group, *The way forward—a new disability policy framework for Australia*, and the National Health and Hospitals Reform Commission final report of June 2009, *A healthier future for all Australians*.

The department is also currently undertaking research in the area of future planning initiatives for families of people with disability. Input has also been provided from jurisdictions through the disability policy and research working group, which is the Commonwealth-state disability officials group. It is worth noting that the main focus of this work is on the future planning needs of older carers. The research is looking at defining future planning, identifying barriers to future planning, identifying best practice features of future planning programs and initiatives, and identifying policy and service delivery gaps.

A key principle underpinning many Australian government initiatives is that support for people with disability, their families and carers is a social investment, as it assists people to realise their potential and enables them to contribute to society economically and socially. Another principle is the notion that increased independence of people with disability will have a fundamental impact on the informal care support that is needed. Strategies that support the independence and wellbeing of people with disability will reduce their dependence on both formal and informal supports and increase their ability to participate in the community, thus broadening the future planning options for themselves and their carers in the future and allowing them to shape their own lives. These strategies include a focus on early intervention, person centred approaches and improving inclusion of people with disability within the Australian community.

I would now like to speak to the committee’s terms of reference. The first term of reference refers to inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers. The aforementioned reports and research provide information about the issues which make it difficult for people with disability who are ageing and their carers to have choice or plan for the future. Descriptions and expectations about future planning are diverse, and any planning activities need to consider the challenges of the past and what may happen, and this is expected to happen in the future.

Apart from the immediate challenges that face people with a disability and carers in relation to drawing on their own limited resources and energies, it appears that planning has tended to be crisis driven. By focusing on short-term immediate needs, planning may not make provision for future changes that affect the person with disability such as the need to change living arrangements or the need for additional care services. Policy gaps have impacted the ability to provide services and the consequent planning capacity of people with disability and their carers.

One of the major policy gaps has been the lack of a nationally consistent policy framework for carers that includes consideration of the future planning needs of older carers. In the Australian government response to the *Who cares ...?* report, the government agreed to develop a national carer recognition framework that includes a national carer strategy. A number of state and territory governments also have strategies, policies or action plans to support carers, and I can provide more information on these if required.

The programs and information relating to the future planning needs for Indigenous Australians and people from non-English-speaking backgrounds can also be difficult to access. The challenges that we are aware of include the fact that increasing lifespan of people with disability, combined with an ageing population and increased workforce participation of female carers, may mean that there is a growing need for formal support such as respite and accommodation support. Limited access to accommodation support means that places may become available only at a point of crisis. This may lead to a lack of desire to plan, where carers feel there is no point in planning for the future, as they feel there are no accommodation or support places available. Fragmented service provision may mean that older carers do not know where to go to obtain information about or assistance in planning for the future and that service providers are also not sure where to direct people to address their issues and concerns. There are difficulties in accessing information and assistance around legal and financial issues, including the concerns about the financial capacity of carers or people with disability to support future care and support arrangements. Carers may also find themselves having to face issues that are difficult to examine, including personal, sensitive, private or confidential matters such as their own mortality; expectations and beliefs about family support; or a loss of control and sense of self. There are also many carers who are not known to government or support services or who may not identify as carers, and it can be difficult to reach these with provision of information about future planning.

Now I will move to your second term of reference. The Australian government, together with jurisdictions, has been working on a number of initiatives to better support people with disability and their carers to ensure continued quality of life for people with a disability as they and their carers age. As previously mentioned, these initiatives have a flow-on effect to people’s ability to plan for the future. The key long-term strategies that are in place or under development, as I have mentioned before, are the National Disability Strategy, the National Carer Strategy, the National Mental Health Strategy and the National Disability Agreement.

The National Disability Strategy is a principal mechanism to progress and build mainstream whole-of-government initiatives. The strategy will align policy and programs with the UN Convention on the Rights of Persons with Disabilities. The purpose of the convention is:

> … to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Governments in Australia are committed to taking action in accordance with this and to providing leadership for the broad community towards the shared vision of an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens. The strategy provides a framework to provide policies and program development by all levels of government and actions by the whole community over the next 10 years. COAG will oversee implementation and monitor progress in the six policy areas.

The National Disability Agreement, which was implemented on 1 January 2009, aims to improve and expand services for people with disability and their families and carers. The new agreement paves the way for significant reforms to disability service systems and incorporates an ambitious National Disability Reform Agenda that was agreed by disability ministers from all jurisdictions in July 2008. A number of reforms under the agreement will address both difficulty in accessing support through the service system and, consequently, many current difficulties in planning to access that support. The agreement includes a focus on providing a person-centred approach to service delivery. This approach includes the person with disability and their family and carers having choice and control over their own lives and the supports they receive. Future planning may be seen as a similar concept to person-centred planning being progressed under the agreement, as both are focused on considering the lifelong needs of the person with disability and their family and carers in preparation for known transition points.

As mentioned before, many older carers may not be connected or may have limited connection to the service system, and the concept of person-centred planning may not be fully understood. Therefore, incorporating this concept into future planning programs and initiatives for the current cohort of older carers is important. Under the agreement, several priority areas will specifically support the future planning needs of people with disability who are ageing and their carers, and I can speak further on a number of these priority areas if required.

The National Carer Strategy will be aligned with the reforms identified in the national disability agreement, in particular the priorities of service planning and strategies to simplify access, early intervention and prevention, lifelong planning, increasing independence and social participation strategies, and improved access to disability care. The National Carer Strategy is part of the National Carer Recognition Framework, the development of which the Australian government is leading. The other part of the National Carer Recognition Framework is the Carer Recognition Bill 2010, which the committee would know was passed by the parliament on 28 October this year and is awaiting royal assent. The cornerstone of the bill is the statement for carers, which sets out 10 principles that Commonwealth government agencies and funded organisations need to adopt in developing policies and delivering services for carers and the people they care for.

The National Carer Strategy is a second step in better recognising and supporting the needs of carers. This strategy, to be delivered in the first half of 2011, will be developed in consultation with state and territory governments with input from carers, key peak organisations and service providers. It will have a 10-year agenda for better sporting carers. It will include shorter three-year plans that will set directions to be taken by government agencies and non-government organisations that work with carers. Our discussion paper was released on 18 October and it is available online. I can provide copies of that later if required. The discussion paper outlines the government’s intention to achieve better recognition for carers along with better information and support, better education and training, better support to help carers work and improved health and wellbeing for carers.

The government is progressing a number of initiatives in recognition of the immediate needs faced by people with disability who are ageing and their carers. There was the $1.8 billion previous disability assistance package funding that was matched by state and territory governments to provide 24,800 additional disability places and an additional $100 million in capital funds for supported accommodation places. Recently the Australian government also announced an additional $60 million over four years to build 150 new and innovative community based respite or supported accommodation places for people with disability, and this money will go towards addressing the shortfall in supported accommodation and respite for people with disability, their carers and families.

The Better Start for Children with Disability initiative will provide $122 million over four years for early intervention services for children diagnosed with sight and hearing impairments, cerebral palsy, Down syndrome or fragile X syndrome. There is $10.5 million in funding to 2013 to continue to support 262 ‘my time’ peer support groups across Australia and to expand the age limit to carers of children with disability up to 16 years. Young carers will continue to be supported with flexible respite, education, information, referrals, advice and support, with funding of $25 million over the next three years. In the mental health sector, the Australian government has committed to working with states and territories in the scope of mental health service system reform. There are a number of mental health programs and we will talk about those later if required.

Coinciding with the launch of the draft national disability strategy, the Australian government also announced a package of five community participation of initiatives to remove barriers and expand the opportunities for people with disability and their carers. I can provide further information on these if required. The government has also progressed reforms in the administration of disability advocacy services, including the development of a National Disability Advocacy Program, which is aimed at providing governments with a consistent foundation from which to deliver disability advocacy services. These initiatives will have a significant impact in the future when those people who are supported are making future planning decisions of their own. There are a number of other financial and legal tools already in place across jurisdictions which support future planning. These include will and estate planning; powers of attorney in relation to financial affairs; guardianship in relation to lifestyle decisions relating to health, accommodation and access to services; financial management orders; trusts; advanced carer planning; and family agreements.

The Australian government has a number of initiatives currently in place to support future planning. These are: special disability trusts, which are set up to assist family members who have the financial means to do so, to make private financial provisions for the current and future care and accommodation needs of their family member with severe disability; an information package; family relationship services for carers; and access to financial advisers. In addition, states and territories have recently developed future planning programs that I am happy to cover later.

I would now like to move to your third term of reference. Future options and services that could be developed to help people with disability and their carers to plan for their future will very much depend on the outcomes of consultations on the National Carer Strategy and the Productivity Commission inquiry. The Australian government will ensure that any options developed in relation to future planning are considered in light of the aims and objectives of the National Disability Strategy, the National Disability Agreement, the National Carer Strategy and the National Mental Health Strategy. I can go into those further, though I think I have covered them.

On your last term of reference, and as I previously mentioned, the department is currently undertaking research in the area of future planning initiatives for families of people with disabilities, focusing on the needs of older carers, with input from all jurisdictions. This work, together with the PC inquiry, the reforms to the disability services system under the National Disability Agreement and the development of the National Disability Strategy and the National Carer Strategy, will guide the development and implementation of policies, programs and services to support carers over the next 10 years.

I would like to finish with some information about the National Carer Strategy consultations. As I said previously, the discussion paper has been released. Public comment on the discussion paper is invited by 5 December 2010. Both the Australian government and Carers Australia are conducting workshops in November and early December. Organisations and service providers can register their interest in attending workshops. I can provide further details on those. Thank you.

Senator BOYCE—Ms Bedford, could you tell us a little bit more about the research that you are doing into the future planning and barriers to planning? How is it being conducted and by whom?

Ms Bedford—It is being conducted through the Disability Officials Working Group under the Commonwealth and state community and disability services ministers council. It is basically a stocktake of future planning options and programs that are available in Australia.

Senator BOYCE—That was going to be one of my questions—if you had a list of the organisations that currently offer planning to carers of people with mental health and disability problems.

Ms Bedford—We do have a list.

Senator BOYCE—We have received submissions from some of those organisations, but within the disability community I am not sure that anyone feels they know all the organisations working in this space.

Ms Bedford—We have a draft report, a report that has not been released, and one of the attachments is a list of the programs current at that time—as you know, some of them come and go. I will just check with my colleagues in the states that they do not want to add anything to their lists and that they are happy for us to provide them.

Senator BOYCE—When does this draft report become a report and when will it be published?

Ms Bedford—It has been to ministers. We will go back and ask them if that can be released.

Senator BOYCE—Is that by FaHCSIA?

Ms Bedford—It was joint. It would be released as part of the disability officials' work.

Senator BOYCE—Is there anything you can tell us about results that research now?

Ms Bedford—I have read out some of the findings. I can give you some information on different states, but that is quite a fair bit of information.

Senator BOYCE—Sorry, what do you mean when you say information on different states?

Ms Bedford—What programs are available in different states.

Senator BOYCE—If you are able to table that, that would be useful.

Ms Bedford—I will seek permission to send it to the secretariat, if that is okay?

Senator BOYCE—Yes. You spoke about barriers to planning. Can you tell us about the barriers to planning as the department understands them?

Ms Bedford—Some of the challenges?

Senator BOYCE—Yes.

Ms Bedford—We talked about the increasing life span of people with a disability and the ageing of the population, which I think we have all seen through the *Intergenerational report* and the expected increased workforce participation of female carers, which I think is certainly a barrier and a challenge that many of us know about that will affect the availability of the informal support for people with disability. That has also led to the increased need for formal support such as respite and accommodation support.

Senator BOYCE—Some of the submissions talk about the difficulty of planning whilst undertaking what is sometimes very onerous full-time care. Have you looked at that issue?

Ms Bedford—That is certainly one of the issues that have been looked at in that stock-take of planning and future planning programs that are available. Some of those programs offer respite or some sort of break for carers to be able to have some time to think about future planning and go and access advice during that planning. Certainly the development of the National Disability Strategy and the national disability agreement is aimed at addressing the needs of carers on the way through—so early intervention and planning from the beginning, either from birth or when someone acquires a disability, and understanding that you have also got a cohort of older carers who have urgent needs now. What we are trying to do is address people on the way through the system but also people that are in the system now that need assistance—

Senator BOYCE—Urgently.

Ms Bedford—Yes.

Senator BOYCE—Could you explain to me what is there in terms of planning for people who currently have urgent needs to develop.

Ms Bedford—In relation to increasing the number of places and increasing supported accommodation out there, a number of states have also increased their investment in accommodation and support.

Senator BOYCE—When you say 'accommodation and support', do you mean support in the accommodation or accommodation and other support?

Ms Bedford—As I am sure you are aware, through the National Disability Strategy there has been quite a push to separate tenancy and support, so there has been increased use of the Social Housing Initiative to support people with disability, so that the tenancy arrangement is separate to the support. The increase in person centred funding or individual funding often allows people to go into those arrangements with those two elements of their life separated—the tenancy and support.

Senator BOYCE—This is sort of a qualitative question, but what level of comfort do you believe carers have out of the ability for someone to go into supported accommodation?

Ms Bedford—I do not know if I can answer that.

Senator BOYCE—Your research did not look at how satisfied or otherwise people were with what was available if they were needing to plan urgently?

Ms Bedford—A number of parents work to be part of the management committees or part of the setting up of some of the supported accommodation options, and the recently announced $60 million initiative is around innovation and allowing community and family groups to look at those new options or some more innovative responses. Some of those families have done years and years of work trying to get support and accommodation options that would suit their children, adult children. They might have some friends that they have been with all the way through early intervention, through school et cetera and they want to live in some sort of close proximity to each other, so those are the sorts of solutions or innovations that that $60 million is going towards.

Senator BOYCE—I guess this inquiry is not so much about those families that have had the ability to do that planning themselves, but the many, many families who, for a million different reasons, have not been able to do that planning themselves.

Ms Bedford—Some of that comes from the stocktake and some comes from ministerial correspondence for which we prepare responses for the minister or parliamentary secretary. It depends on the level of engagement of the family within that accommodation setting. Some service providers seem to relate well to families and others maybe not so well. It depends on the circumstances. Often it seems to depend on where the decision-making around that accommodation sits. So if a person has their own funding, or a funding package that they can access, and can move around if they are not happy with a provider to try to see if there is a better option, they seem to me to be more satisfied with their choices.

Senator BOYCE—But generally the availability of options to move around would be somewhat limited, wouldn’t it? There is not enough accommodation, full stop.

Ms Bedford—No, there is not.

Senator BOYCE—So there are probably only very limited chances to say, ‘I don’t like this one; I will go somewhere else.’

Ms Bedford—You probably have more options if you have your own funding pool to move with you.

Senator BOYCE—Would you have any sense of how many people do have individualised funding—packages—compared to those who do not? We are partly in the area of unmet need here, but also in the area of policy development.

Ms Bedford—I do have some information, but I do not have it with me. There are numbers in the report on government services. That includes some figures from the employment services, which are more around case based funding, but we can pull out some of that data for you.

Senator BOYCE—When you talk about people choosing to change their accommodation to something they think is going to be more suitable for them, what sort of percentages of people with disabilities or mental health problems would be doing that?

Ms Bedford—As I said, some of what I was reporting was information that I had from people writing letters—I do not have an AIHW-type figure.

Senator BOYCE—Would I be right in suggesting that it is probably individuals who have been so upset by whatever their current level of accommodation is, for whatever reason, that they have been prompted to write to the minister or the department about it?

Ms Bedford—They would be the letters that we would receive.

Senator BOYCE—So it is quite minimal. Lots of the correspondence talks about the confusion that service users have about where to get things, how to get them, what the states do, what the Commonwealth does et cetera. There are a number of suggestions in the submissions about one-stop-shop approaches or resources that would make it easier for people who want to plan. What is the government or the department doing there?

Ms Bedford—Through the National Disability Agreement, we are certainly looking through the priorities and exploring and working on common principles around access. I understand that you will be talking to the Department of Health and Ageing at some point and they are certainly progressing one stop shops as part of the hospital and health reforms, or they are talking to states about one stop shops as part of those reforms. That sits within their area of responsibility. But certainly there is no wrong door approach in the disability policy agenda.

Senator BOYCE—I think a lot of people in the sector might characterise it more as ‘no right door’ than ‘no wrong door’! That is just a comment. I appreciate what you are saying, but could you give me some actual detail on what is being done to make it easier for people to find out what is out there?

Ms Bedford—We need to work with officials to progress the outcomes of the national stocktake on future planning—whether that goes forward as a package of information or whether we have state packages that are linked to a national package. The national stocktake has all those programs. Is that what you mean?

Senator BOYCE—I meant not so much the programs but the actual government services and programs that are available to someone who might currently be looking at planning. Pretty much every submission—from service provider organisations, even, and from individuals—says that it is very confusing and very difficult. One of the barriers to planning, in fact, is that inability that people have to find out where the buckets are, so to speak, to assist them. You have mentioned the common principles, but could you put some more detail into what you are doing there?

Ms Bedford—Sure. May I go through priorities (e) and (j) under the national reform agenda of the National Disability Agreement?

Senator BOYCE—Yes, please.

Ms Bedford—Priority (e) is that the National Framework for Service Planning and Access will focus on ‘providing a person centred approach to service delivery and to simplify access to specialist disability services’. Priority (j)—improved access to disability care—is:

> Systems that improve access to disability care and ensure people are referred to the most appropriate disability services and supports, including consideration of single access points and national consistent assessment processes in line with nationally agreed principles by end 2011.

Senator BOYCE—Is the intention that we would have single access points—perhaps state based single access points—by the end of 2011?

Ms Bedford—The Australian government would certainly like to have single access points, but you will note the careful wording about ‘consideration of’.

Senator BOYCE—I noticed that it said ‘consideration’; that is why I am asking the question.

Ms Bedford—As you would understand, Senator, some of this takes a while to get to.

Senator BOYCE—Yes.

Ms Bedford—In November 2008, the Community and Disability Services Ministers Advisory Council endorsed the national service planning and access improvement framework. Implementation of the framework commenced in January 2009. The framework is supported by a ‘shared principles of key terms’ document, which outlines a common understanding of the core concepts—simplified access, single access points, person centred approaches, assessment process, continuum of funding approaches and service planning—to assist jurisdictions in implementing the national framework at a local level. All jurisdictions have considered how reforms have achieved simplified access, any remaining challenges and further plans to simplify access. Jurisdictions will shortly finalise an implementation plan and mid-term progress report.

Senator BOYCE—You were talking about simplified access being set up in 2009 as a priority objective. All these submissions have come in in late 2010. They do not appear to suggest that the users of services think that the access has been simplified. You are saying that ‘hopefully’ by the end of 2011 there could be simplified access. What has actually happened between the beginning of 2009 and now to simplify access?

Ms Bedford—They have agreed to the principles and they are aligning their programs with those. I do not think I can give you much there.

Senator BOYCE—I am looking for things such as whether a person has been appointed to do X or Y.

Ms Bedford—Jurisdictions share information on these priorities at some of the ministers’ meetings. I could pull out some of that information and provide it to you.

Senator BOYCE—If you could do that on notice, Ms Bedford, that would be useful.

Ms Bedford—I am happy to do that.

Senator BOYCE—I think it was the NDIS submission that made the point that carers and their adult child with a disability or a mental health problem only come to the notice of the system when the carer can no longer care. Are you able to give me a sense of how common that is? Is it the majority of people who are urgent planning cases?

Ms Bedford—I can go back to when the department was implementing the disability assistance package in 2007—

Senator BOYCE—Is that when you did the audit?

Ms Bedford—Yes, with carers. There were a number of families in the Centrelink system. You might have had access to that report. If not, I can give you that report. I do not have the numbers with me, but a number of carers had access to payments but they did not have any access to services. When we did the consultations for the supported accommodation, carers turned up who were not part of the Centrelink system. I have seen figures in some reports from community groups that say that 25 per cent of carers are not in the system at all.

Senator BOYCE—That is anecdotal?

Ms Bedford—Yes.

Senator BOYCE—There is a significant group—let us not use the 25 per cent—who do not even claim the disability support pension, then there is another group who claim the disability support pension but have nothing else or have no other contact with the system.

Ms Bedford—They have had contact with the system and moved out of the system for some reason.

Senator BOYCE—One of those reasons would be a lack of trust in the system?

Ms Bedford—That is what some carers have said. It is anecdotal.

Senator BOYCE—They have perhaps said that services were not available when they needed them or did not meet their expectations and so on?

Ms Bedford—Yes.

Senator BOYCE—What percentage of people with a disability and/or mental health problems and their carers would have the DSP and use services?

Ms Bedford—I do not have those sorts of figures.

Senator BOYCE—Are those figures known?

Ms Bedford—That data is not linked—that I am aware of.

Senator BOYCE—So there is no way of ascertaining if X number of people who get the DSP from Centrelink but only X number of people use support services or other packages of any sort?

Ms Rose—I am certainly not aware of any data to that effect.

Ms Bedford—Some of the difficulty involves privacy issues and using data for the purpose for which it is collected—especially the DSP.

Senator BOYCE—I see it as an aggregated amount. It seems to me it is one way of measuring unmet need. What is your estimate of unmet need in the disability area? Do we need to talk about that in regard to accommodation and support services et cetera?

Ms Bedford—I think you asked me that at Senate estimates, Senator.

Senator BOYCE—I did.

Ms Bedford—I think I mentioned then that we are still waiting for the 2009 ESDAC data, and AIHW with disability officials would be looking at an update of that.

Senator BOYCE—When would you anticipate that coming, Ms Bedford?

Ms Bedford—I have got the SDAC schedule here: the summary publication is expected on 28 April 2011.

Senator BOYCE—So at least it should be in time for the Productivity Commission.

Ms Bedford—Yes. We also talked at Senate estimates around the national need and supply model. I think you have some questions on notice we are preparing responses to, so we are doing that around that. In June 2005—I think you have seen those figures; they are the last ones we have had.

Senator BOYCE—Yes. Are you confident that the unmet need figures actually reflect unmet need or do you suspect that, given as we have discussed, a lot of carers and people with disabilities only come to the attention of the system when the care fails; do you think it is an underestimate?

Ms Bedford—If the waiting lists have an impact on the unmet need figures then your hypothesis would be that if people are not on waiting lists then they would be—

Senator BOYCE—In fact there are submissions here—

Ms Bedford—Yes, that is right.

Senator BOYCE—saying people did not know there was a waiting list.

Ms Bedford—That is right, but if we go with the SDAC figures—that is people self-identifying through questions—that might give you information on whether or not they are getting services. That would be a clearer picture.

Senator BOYCE—I will go back to your barriers to planning and the like. Is there consideration of sustainability within those planning options? Some of the submissions mention it, but there is also a lack of trust that people often have for government services in that it can be the flavour of the month or the flavour of the year type service and then suddenly it is no longer available. How would you sustain long-term planning, given that the point of it is to have the planning continuing to happen after the parents or carers are no longer able to provide it?

Ms Bedford—A number of states are framing their program responses in reassurance, trying to provide better long-term support for carers. I understand that their policy—

Senator BOYCE—We are ultimately talking about a time when the carer, who is often a parent, is not able to care.

Ms Bedford—With regard to policy responses, I am thinking about New South Wales and Queensland with the recent budget funding there. We are trying to bring the carers into the planning options for future planning for people with disability. That seemed to be one of the ways they were trying to provide more surety for carers on the way through, involving the families. The way some of those programs were described seemed to be bringing a policy response that involved families as best they could in providing longer-term care.

Senator BOYCE—To involve families in establishing ways of providing care after their own deaths or inability to care.

Ms Bedford—Yes, ways to provide longer-term care. As I mentioned before, the $60 million is around capital works on the ground, to assist carers to have the infrastructure, a home environment or whatever suits those families best, and then to have the support from individual funding or state and territory government support.

Senator BOYCE—We have talked about the urgency and whatever of the situation. In the average Australian home the children of the home would be expected to move out into accommodation of their choice in their late teens to their mid-thirties or something.

Ms Bedford—It is getting older, I think.

Senator BOYCE—That is right; they are getting older. Twenty or 30 years ago, you would have said that everyone would have been gone by late their late twenties but that is no longer the case. Much of what I read here appears to be predicated on the basis that the person with a disability is going to live with the parent until the parent is unable to care for them—that they would be living at home with their parent or carer for 30-40 years. Is this the basis for the current planning?

Ms Bedford—I do not think it is. Certainly the National Disability Strategy is about having better access right across the community, from early childhood education to post school—that people with disabilities would be part of the community, as they should be, and that, if we can get better mainstream outcomes for people and more welcoming and accepting communities, looking after people or caring for them in their parents’ home should not have to be a long-term commitment by carers or the person with a disability.

Senator BOYCE—That happens quite a lot now. What are the barriers to what we are saying is an average life?

Ms Bedford—Some of the barriers are that we need to get better outcomes, as I said, across all mainstream areas, including early childhood education et cetera, better housing options—

Senator BOYCE—But we are not expecting people to move out of home when they are in early childhood education.

Ms Bedford—No, but if people get the early intervention that they need, often they can be more independent.

Senator BOYCE—But the point is not whether they are more independent, is it?

Ms Bedford—Sometimes it is.

Senator BOYCE—You are not saying that, if they are more dependent, they should continue to live with their parents.

Ms Bedford—No, I am not saying that. I am saying that we are hoping that, through the National Disability Strategy and the national disability agreement we would help people live full lives in the community.

Senator BOYCE—Absolutely.

Ms Bedford—I have seen some of the things that you have written and you have certainly been supporting that view. The other important part of the disability policy is the Productivity Commission inquiry into lifetime care.

Senator BOYCE—This inquiry was seen as complementary to that, not in any way competitive with it, so to speak—looking at perhaps some of the more intangible issues around planning for the future. A number of the submissions raised the point that deinstitutionalisation policies, which are great, have led to a situation where older people with disabilities cannot have retirement village type situations, which is the way we provide for other older Australians. I have the view that retirement villages are institutions but they appear to be institutions that Australians want. Could you comment on the clash of policy on deinstitutionalisation and small groups compared with the way we allow retirement village planning to happen.

Ms Bedford—I am not sure about your question.

Senator BOYCE—A person without a disability would quite willingly at some stage in their life—or a lot of people do—move into a retirement village situation where there are lots of people like them. The policy around not allowing institution like living for people with disabilities, which is to be commended, means that that cannot happen for older people with disabilities. My preference would be that we think of another way of doing retirement villages. Some of the submissions have made the point that there is a sort of reverse discrimination going on here in that there cannot be a retirement village type setting for older people with disabilities.

Ms Bedford—So they are seen as reinstitutionalising people.

Senator BOYCE—Yes.

Ms Bedford—A lot of people’s preference, whether or not they have a disability, would be to age at home.

Senator BOYCE—Absolutely.

Ms Bedford—If people have been in a group home situation with the same people for a number of years they might want to stay there as they age.

Senator BOYCE—Absolutely. Ageing in place is something that has also been raised, but I want to know views on—

Ms Bedford—A number of people, organisations and governments would be concerned about reinstitutionalising people with a disability. There would be some families that would see a congruent care type setting, whether it is a retirement village or something like that, as one of the solutions that they would be interested in. There would be advocacy groups that would very much be against that sort of setting. So it is quite complex.

Senator BOYCE—But it is, nevertheless, something of an anomaly that we have no problem with older people without disabilities choosing to move into retirement village settings but that current policy does not allow people with disabilities to do the same. I am not sure which policy we should be changing, but it seems to me that it is something we need to look at.

Ms Bedford—Certainly, and there would probably be some advocacy groups that thought that retirement villages for older people were not really appropriate.

Senator BOYCE—Absolutely. I am aware of a number of academics who argue that retirement villages are institutions anyway. Nevertheless, whilst we are talking about normalising behaviour, that is one of the things that is considered normal for older Australians to choose to do.

CHAIR—It also depends on your definition of community. I know a number of Australians who are not old who choose to live in communities, in clustered housing, because that is the way they want to bring up their families. I know of a number of examples where that is occurring. Some people see that as a positive. I suppose it is about whether you have made a decision to do that or whether it has been forced on you.

Ms Bedford—Some people living in a unit by themselves, depending on their care arrangements, would think that they were institutionalised because of the arrangements, even though they might have more freedom.

Senator BOYCE—Absolutely. Look at how many young people move out by themselves.

Ms Bedford—So it is quite a complex area.

Senator FURNER—Earlier you responded to a question from Senator Boyce about some of the people who have put in submissions wanting clarification on jurisdictional responsibilities of particular programs. I am wondering what the department can respond to with regard to this booklet: *Planning for the future: people with disability*. Has that been a process that has allowed people a greater opportunity to have an understanding of what is available for carers or persons with disabilities?

Ms Bedford—The feedback on that booklet has been quite positive. In a fairly straightforward manner it has set out options for people.

Senator FURNER—When you say ‘quite positive’, can you give us some results, such as website hits?

Ms Bedford—I do not have them with me.

Senator FURNER—Maybe you could provide them on notice.

Ms Bedford—Yes, we could.

Senator FURNER—What are the aims of the booklet? Are they to provide a better understanding of what is available for carers?

Ms Bedford—Yes, to provide a fairly easy, accessible format for people to be able to break down issues and work through those different elements.

Senator FURNER—How long has the booklet been in circulation?

Ms Bedford—Since 2007.

Senator FURNER—Are there intentions of updating it shortly or in the not-to-distant future?

Ms Bedford—We are quite interesting in updating it following the national stocktake. We may need to adjust the information in that booklet. I would say yes, we are quite interested in looking at it to see if there is a revised product for which we might want to seek government’s agreement to publish.

Senator FURNER—Going back to clarity and jurisdictional responsibilities, would you suggest there is adequate information out there for people to be aware of what is available?

Ms Bedford—There seem to be many programs out there and many policies but there does not seem to be something that provides the information readily on all the different products. That was part of the idea of doing the national stocktake: to get the information and seeing what we could do about bringing that together for people.

Senator FURNER—What is the department’s response to suggestions that there is a lack of communication between the relevant departments? I think one submitter indicated that it does appear that departments talk to one another.

Ms Bedford—Departments talk to each other frequently but it is on a range of issues. The impetus for this national stocktake was to find out what was going on out there and how we could bring it together. I think we all recognise that that is an important thing to do.

Senator FURNER—That is fair enough. Also—you might need to provide this on notice—you mentioned earlier that 25 per cent of carers are not in the system, and that was anecdotal evidence. Are you able to provide the numbers of carers in the system currently that are recognised?

Ms Bedford—It depends which system it is. We can provide some data on carer payment and carer allowance. As I said to Senator Boyce before about the linking of payments and service data, the data is not linked.

Ms Rose—Senator, the number of people in receipt of carer payments at the end of June 2010 was 168,913.

Senator BOYCE—That is asset and income tested too, isn’t it?

Ms Rose—Yes, it is, but for carer allowance, which is not asset and income tested, the total for the same period was 495,733.

Senator FURNER—I might go to the SDTs. I understand the department’s submission indicated that as of 31 March this year there were 91 SDTs operating. On reflection, has that been a reasonable uptake, in the department’s view? Or would you consider it otherwise?

Ms Rose—I think a general view is that the uptake of special disability trusts has not been as high—certainly not as high as originally estimated by FaHCSIA. To bring you up to date, as at 30 September this year there are 119 special disability trusts in operation, but 500 people have been assessed as eligible beneficiaries, including the 119. It just means that people are eligible but they have not gone the next step of setting up a trust.

Senator FURNER—Do you consider that they are in the process of considering those options? I guess that is hard to judge.

Ms Rose—It is hard to judge, but the fact that they have gone to all the trouble to go through the hoops to determine whether they are eligible or not would suggest that they are certainly thinking about it. Also, I understand there are a number of other people who could have decided to establish a trust in their will that we do not about.

Senator FURNER—Over time, I guess, people will become more and more aware. What has the department been doing to make people aware of that opportunity available? What sort of information have you been providing?

Ms Rose—I think that special disability trusts have been quite visible in recent estimates hearings, and so on, and there was a Senate inquiry. In the 2009-10 budget the government announced that certain taxation benefits would apply and in the current budget there were other measures. From 1 January 2011 people with disability who are beneficiaries of a trust will be able to work up to seven hours a week in the open labour market and still qualify for a trust. That is something new. The trust will be able to pay for the beneficiary’s medical expenses including membership costs for private health funds and the maintenance of the trust’s property. The trust will also be able to spend up to $10,000 in a financial year on discretionary items not related to the care and accommodation needs of the beneficiary of the trust and there is an undertaking that government will undertake a review of the amount that can be held in the trust on a concessional basis, the amount that can be gifted and who can request audits. Also, the FaHCSIA and Centrelink websites have that information on them.

CHAIR—When are the reviews taking place?

Ms Rose—That would be January 2013.

CHAIR—So that is the two-year review.

Ms Rose—Yes, from the implementation of this, and the bill is before the House.

Senator FURNER—Is there any consideration being looked at in terms of capital gains tax on SDTs?

Ms Rose—Yes, that was one of the 2009-10 measures. We understand that legislation will be introduced in 2011 which will extend the capital gains tax main residence exemption to include a residence that is owned by an SDT and used by the relevant beneficiary as their main residence.

The other part of that 2009-10 budget measure was that starting from 2008-09 financial year unexpended income of a special disability trust will be taxed at the beneficiary’s personal income tax rates rather than the highest marginal tax rate, and that received royal assent in June of this year.

Senator FURNER—Some of the submitters also indicated that the SDT scheme lacks flexibility and is too complex. Do you have a response to those suggestions?

Ms Rose—I think that in terms of flexibility the measures that were in the current budget year do go to some of that for discretionary spending and so on. I suppose those measures are really the main response to that—regarding discretionary expenditure and medical expenses and so on. It does give $10,000 a year that people can use on things not directly related to the purpose of the trust.

CHAIR—I understand that ‘medical expenses’ have now been broadened. Previously medical expenses related to the disability. My understanding now is that medical expenses per se—

Ms Rose—Yes, including membership of health funds and so on.

CHAIR—And that is different from the $10,000—

Ms Rose—Yes, it is. It is completely separate.

CHAIR—It was something that you said that made me think maybe the medical expenses were going into discretionary funds, but they are completely separate, are they?

Ms Rose—Yes.

CHAIR—Yes, that is what I thought.

Senator FURNER—Ms Bedford, coming back to the NDA, you covered off on the contemporary delivery of services such as, I think it was, 6,200 respite places, 2,300 individual service packages and so on. Are you able to give a forward projection on individual service packages? Are you able to give a forward projection as to how the rest of that money will be delivered with the increased expenditure in the NDA?

Ms Bedford—The 24,000 places are well on the way to being delivered.

Senator FURNER—So they are tracking on protection.

Ms Bedford—Actually they are tracking faster than projection.

Senator FURNER—How much faster? Could you take that question on notice?

Ms Bedford—We have released the figures previously and they are tracking.

CHAIR—Could we go to how HACC and community services fits into all this? Specifically I am interested as to how the review and the new process, which I understand is still ongoing, fit into all the other work that you are doing in this area. We have been talking about the National Disability Agreement and my understanding is that—we have discussed this before—the Commonwealth will take ageing and the states take disabilities. There is the ongoing process of refining HACC. I am wondering how you see that in terms of where the Commonwealth is moving to in delivery. All the programs you have been speaking about very clearly put Commonwealth still in the space of disabilities. How then is that going to relate to the review of HACC and how the new HACC is going to look?

Ms Bedford—Certainly the Commonwealth through DoHA are taking the lead around the health reforms which include the 65-year age split that you have just described. The Commonwealth will take responsibility for the over 65 and the states will take responsibility for the under 65. The Department of Health and Ageing is leading the work around the HACC. As part of the discussions with states through disability officials we are certainly very interested in that work and are working to maintain the policy intent of HACC and align it with disability programs and policy not to change HACC into disability programs and policy but to make sure that the system interfaces well after that split. It is still being discussed between states.

CHAIR—Yes, I am aware of that, and it has been for some time now. Certainly it is still pretty opaque from where we sit.

Senator BOYCE—When will you be able to have HACC services if you live in supported accommodation?

CHAIR—Yes. There is this issue. As you have said, this committee has done a number of inquiries into ageing and disability, and the thing that comes up constantly is that 65 is the transition point for responsibility between the Commonwealth and states. That is, I feel, particularly important for this inquiry and this committee as we are planning for ageing with a disability, because those are the two issues that are dealt with by HACC.

Ms Bedford—Yes, absolutely.

CHAIR—So I really would like to know—it seems to me to be very relevant to this committee—how that planning process is going. Obviously we are going to need to explore that with DoHA.

Ms Bedford—It is going really well. They have the lead, and they are certainly doing the work with HACC areas and with all the states around the HACC aged care.

CHAIR—How are you involved in that process?

Ms Bedford—We are involved in it with discussions across the relevant Commonwealth departments. It also comes up through disability officials groups. Ministers are keeping an eye on it through the various ministerial councils. I think that early next year, in January or February, there is a combined meeting—I have not got the name right—of the aged care and HACC officials group with the disability officials group.

CHAIR—That is early next year?

Ms Bedford—Early next year. In the states they are going through similar processes. There would be one agency with the lead, but they are working with other agencies in the same realm of work around HACC, disability and aged care.

CHAIR—Thank you.

Ms Bedford—Senator Furner, I have found my figures. The most recently available data was, I think, from June last year. There were 6,800 respite or respite effect places, 1,260 intensive in-home support services, 2,300 individual support services and 1,000 supported accommodation services being provided. The data is due to be updated—

Senator BOYCE—Sorry—what are those figures?

Ms Bedford—That is what has been delivered from the previous NDA funding. Those figures are going to be updated in the near future for the next ministers conference.

Senator FURNER—What date will that be?

Ms Bedford—My understanding is that it is in mid-December.

Senator BOYCE—I think questions were asked, not at the last estimates but at the previous estimates, about the family relationship services for carers. Could you tell us a bit about how that is going, how many have used it et cetera.

Ms Rose—Yes. In 2009-10 the providers reported that they saw 3,705 clients.

Senator BOYCE—Can you give us some sense of the issues raised there.

Ms Rose—In what sense?

Senator BOYCE—The numbers who were using it for long-term planning or the numbers that may have, out of that, developed a long-term plan.

Ms Rose—An evaluation report on FRSC was undertaken last year by a company called WestWood Spice. They reported that a very small number of people were assisted for the specific purpose of long-term planning but that the majority of clients were accessing the services for more generic counselling reasons.

Senator BOYCE—So we are talking about people who have a family member with a disability but—

Ms Rose—That was certainly the intent of this program.

Senator BOYCE—Yes. But is the generic counselling for all people who have a family member with a disability or not?

Ms Rose—That is an excellent question. I do not actually know the answer to it at the moment. I have taken that as a given, but I have not actually asked that question. I can get that information for you.

Senator BOYCE—That would be good.

Ms Rose—I have assumed that that is the case, but I will find that out for you.

Senator BOYCE—If it is possible, obviously without breaching any privacy, to get some sense of the types of issues that families with a member with a disability are raising with the family relationship centres, that would be good.

CHAIR—Minister Macklin made an announcement last week about the future role of the ongoing funding and role of the family relationship services. I can remember some of them, but off the top of my head I cannot remember if carers were included in that announcement.

Ms Rose—I do not know. We have not been approached in relation to that. That is a subset of the other program. I am not sure whether that was included or not. I am sorry.

CHAIR—I have the announcement in my office, so I can go back and check. I was just wondering whether you could give us a bit of detail here.

Ms Rose—I am sorry; I can’t.

CHAIR—Thank you. I will chase it up.

Ms Rose—For the committee’s information, a summary report of that evaluation is expected to go up on the FaHCSIA website soon. The whole report will not be going up, because it has information about specific providers and we have had advice that that is commercial in confidence, but a summary report will be prepared.

CHAIR—How soon is 'soon'?

Ms Rose—In the next couple of weeks.

CHAIR—Is that the report that the announcement was made on—

Ms Rose—The evaluation report.

CHAIR—that we have been after for a while?

Senator BOYCE—It would be useful for the committee to have that too, so it would be good if it could be provided to the committee on notice.

Ms Rose—Yes.

Senator BOYCE—Ms Bedford, I am not sure who to address this question to, so I will start here. There is a discussions relationship linkage between FaHCSIA and DoHA in the area of ageing with a disability. Could you tell us how the two departments work currently to try to ensure that you have covered both sides of that issue?

Ms Bedford—As I said previously, we meet regularly around aged care disability.

Senator BOYCE—Is that once a month?

Ms Bedford—It has been once every four to six weeks. We talk quite frequently.

Senator BOYCE—Who meets?

Ms Bedford—It is at the group manager level and branch head level. We also bring together a fair bit of work around the carers work. As part of the response to the *Who cares ...?* report we have a carers forum that includes DoHA, FaHCSIA, PM&C, Finance, Treasury, DEEWR, DVA and Human Services. They meet regularly to make sure that that work is coordinated.

Senator BOYCE—They are all the departments that would deal with carers?

Ms Bedford—Yes, so we can make sure that there is a coordinated response across the Commonwealth government. There is a working group, a smaller group of those agencies, that meets quite frequently, especially in the lead-up to the release of the discussion paper and the consultations. The forum meets every four to eight weeks, and more frequently when there are things such as the consultation happening, to make sure that we have an aligned position on the papers et cetera.

Senator BOYCE—Do you meet in response to issues or to develop issues?

Ms Bedford—The carers forum is really more for planning—gaining an agreement on the way forward. If there was an issue that we needed to respond to that was not something that we had foreseen, we would meet and work through that issue. But up until now it has been issues that we have known about and have been planning—implementing the responses to the W*ho cares ...?* report et cetera.

Senator BOYCE—Can you give me an example of something that the carers forum would work on or has worked on?

Ms Bedford—The Carer Recognition Bill and the discussion paper for the National Carer Strategy are elements that we have worked on.

Senator BOYCE—When you meet with DoHA on ageing and disability issues, what sorts of things are discussed? Can you give me an example of a result?

Ms Bedford—Some of the things that Senator Siewert has been talking about today around interface issues between disability, HACC, the over-65s and under-65s, the older people in disability services—those sorts of issues.

Senator BOYCE—You reminded me of a question I meant to ask in relation to extending the pension age to 67. Will that mean the disability support pension—or all pensions—will be extended similarly?

Ms Rose—I cannot speak about all pensions. I think that is just in relation to the age pension.

Senator BOYCE—So it would not affect the disability support pension as far as you are aware?

Ms Rose—No, and people on DSP are not forced to go onto—

Senator BOYCE—No, but they have to make an election at whatever the age is now.

Ms Rose—Yes.

Senator BOYCE—Would that election be at 67 or not?

Ms Rose—One would imagine that as the qualifying criteria for age pension increases, you would not be able to elect to go onto it until you had reached the threshold that was in place at that time.

CHAIR—You said you imagine that. Could you take that on notice?

Ms Rose—I certainly will.

Senator BOYCE—Yes, if you could confirm that. Obviously a lot of other services cut in or out and, as we have discussed, who is in charge—it happens at 65. Will that then happen at 67? A related question would be the average life expectancy of people with disabilities. I know that is an extraordinarily broad question. I do not know how you might go about answering it. You may have to look at categories. Perhaps we would have to split it into intellectual disability and physical disability or some such. The average life expectancy would be considerably lower in that area.

Ms Rose—We know that the average duration on DSP is nine years, usually followed by some other time on income support, so the average time on income support for someone on DSP is 11 years. Obviously that is an average, because some people come on at 16 and other people come on much later.

Senator BOYCE—I would like to go back to the issue of long-term planning and sustainability. We have had a submission from Carers Australia suggesting that they would be in a position to offer a resource to assist people with knowing what is out there and with planning. You have spoken a lot about person-centred planning. There is, however, a generation of people—if you look at the submissions, you will see this raised—who have come to simply accept what 'they' will give us because they found it too psychologically and emotionally exhausting to keep fighting for what was preferred. What is the department doing to assist people to make what is actually quite a radical mind-shift from what 'they' will give us to dreaming and asking for what they need?

Ms Bedford—I think the consultations around the National Carer Strategy are one thing around seeking people's views rather than giving views to people about how their life should go forward, which is something I hope we have not been doing. It is a difficult space, Senator, when you think that most of these future planning programs are delivered by a state—

Senator BOYCE—It is a difficult space.

Ms Bedford—It is a difficult space. So through working with the states around the national carers' strategy I think there are certainly options, and information and access to assistance around future planning has come up in some of the consultations I have been to. As you said, people are interested in that. I think that is one of the most important avenues at the moment that we have to really talk to carers, and Carers Australia are certainly doing the carers' consultations nationally.

Senator BOYCE—Ms Winkler, are there any specific issues relating to autism that make planning different or more difficult in the area of autism?

Ms Winkler—I cannot really comment on the adult population because the focus of the services—

Senator BOYCE—So you are involved in the current delivery of the education?

Ms Winkler—The early intervention service responses. One arm for government is to try to establish some strategies that are about getting in early to assist people with their developmental potential so that down the track they can engage more effectively in both education and, hopefully, employment opportunities. The direct service delivery responses for older people with autism are primarily in the states' realm at the current time.

Senator BOYCE—I think we might have more questions next time.

CHAIR—Thank you very much. Once we have held all our other hearings, I would like to ask you to come back for a relatively short time—I will see if we can get DoHA as well—to follow up on questions that are inevitably going to come out of the rest of our hearings, if that is okay with you.

Proceedings suspended from 10.32 am to 10.49 am

BAKER, Dr Ken, Chief Executive, National Disability Services

CHAIR—Welcome. I understand that information on parliamentary privilege and the protection of witnesses giving evidence has been provided to you. Should you wish to see a copy of this information, it can be provided by the secretariat. We thank you for your submission: No. 45. I invite you to make an opening statement, if you wish, and then we will ask you some questions.

Dr Baker—Thank you for the opportunity to meet with the committee this morning. NDS, as you are probably aware, represents non-government disability service providers around Australia. But, clearly, it is a key role of disability service providers to work in cooperation and coordination with family carers.

By way of summarising what I see as the key issues facing family carers, I refer to a study which Anglicare Sydney released just last month called *Care to live or live to care?* It is an excellent synopsis of the dilemma, the uncertainty and the stress that face many family carers of people with disability. There were about 300 carers in this study. Two-thirds of them were over 70 years old and one in five was aged over 80. Most were women. Many had been caring for decades; one in three had been caring for more than 40 years. The sons and daughters for whom they were caring had a range of disabilities but predominantly intellectual disability.

As with many national studies of this kind, these carers reported relatively low levels of wellbeing and high levels of stress. Among the factors contributing to their stress was that only one in four of them, despite their age, had a plan for the future care of their son or daughter. Half of them indicated that they did not know or were uncertain about where to get help if they required help. Eight out of 10 were anxious about the future of the son or daughter with disability for whom they cared, and one said, ‘I see no light at the end of the tunnel.’ More than half of them said they needed time out from their caring role. Thirty-nine per cent reported stress from trying to manage the challenging behaviours of a son or daughter and having increasing difficulty doing that. Many felt isolated and did not have a network of family or friends on whom they could draw for support.

This is a bleak picture. It is not a bleak picture because of the presence of disability in these households—none of these people, from my reading of the report, expressed regret at having undertaken what for them was a labour of love. It is bleak because of the lack of support available to these carers.

The study undertook a gap analysis which compared the reported access to a service type that these family carers had and the importance they attached to accessing particular service types. There were two areas where the gaps were greatest between what the families felt they needed and what they had. The development of a transition plan was the highest gap. Four out of five carers ranked this as important, but only one in 10 had been supported by a service to develop such a plan. The second highest gap was assistance for the person with disability to pursue their goals and interests outside the home.

The ageing carers in this study, like an increasing number around Australia, are past the age at which most of us would retire. Their long-time work in supporting a son or daughter has been a labour of love; they do not regret doing it. But I think society has an obligation to provide these people with greater certainty and greater peace of mind about the future care and support of their son or daughter. We cannot do that in any systematic way without overhauling the basis on which we fund and provide disability services. Thank you.

Senator BOYCE—Dr Baker, I have to follow up on your last comment. Could you explain further how you see the funding of disability services being reformed to meet those needs?

Dr Baker—I guess up until now the approach to the funding of disability services has been ad hoc in response to—

Senator BOYCE—Squeaky wheels?

Dr Baker—squeaky wheels and to pressures on the system reaching crisis point. It has not been informed by any sense of long-term planning, so there has almost been a reluctance, I think, to collect data on what the current need for services is and, even more so, on what the future need will be. There are, as you are aware, some promising signs of change, the most promising being the Productivity Commission’s inquiry into care and support for people with disability. If that inquiry delivers what I hope it will deliver, it will be not a patching-up of the system, but a complete renovation of the system—a rebuilding of a system which I think is in severe disrepair at present.

Senator BOYCE—You would have heard me ask FaHCSIA earlier about what was being done to assist older parents who often were disenchanted with the system and had simply copped what was being handed out because they did not have the energy to do anything else. Moving to a person centred approach requires quite a bit of energy, quite a bit of thinking, quite a bit of planning. What would you see as being necessary to help carers and older people with disabilities to deal with that mind shift?

Dr Baker—I think you are quite right in describing that as a mind shift. It would be quite a substantial shift in the whole culture of the system. The culture of the current system is built around family carers and people with disabilities being mendicants and therefore grateful for whatever they get and hanging on to whatever they get, because they fear that if they let it go they will not get anything else. If we were to move to a system based upon entitlement to service, a system that was more equitable than the one we have at present, a system that respected the choices of carers, I think it would greatly empower those carers and people with disabilities and their frame of mind would shift from being grateful and clinging on to whatever they get to being more adventurous in their choices, toward wanting to exercise choice, toward holding service providers accountable for the quality of support they provide.

I think the person centred planning which you mentioned is a key part of this transition—to move from a system that is service-centric, that has been built around standardised, ‘one size fits all’ services to a system built around the needs of the individual is, I think, a key part of this change. So if we get a new system, which I hope will be built upon a national disability insurance scheme, the new system will not be more of the same; it will be more, but it will be more of something different. Many service organisations are making this transition at present as best they can within the current funding constraints, but the constraints are very severe—the rules of rationing services and funding are very severe and limit greatly the choices that people could be offered.

Senator BOYCE—The Carers Australia submission notes that:

> Some carers may need significant assistance, information or even counselling before they can even begin to ‘think’ long-term.

Could you comment on that statement?

Dr Baker—I entirely agree with that. What has been striking not just from the Anglicare Sydney study but from an earlier study of maybe five years ago by Scope Victoria is the extent to which people overestimated their capacity to continue a caring role long into the future. People well into their 70s are anticipating in the Scope study that they can continue to care for another 20 years.

Senator BOYCE—That is hopeful, I suppose.

Dr Baker—It is hopeful—it is very optimistic. It is very unlikely that they can do that, or at least do it without substantial support. Planning is complex for people. It involves not just working with the service system but also thinking about the financial implications of decisions. There maybe issues of guardianship, so legal issues. Family carers are typically so absorbed in their day to day tasks of providing that care and support that they do not have the opportunity, they do not have the information, they do not have the support to be able to make those decisions about the longer term.

Senator BOYCE—Do you have 650 member organisations?

Dr Baker—In fact it is 700 now.

Senator BOYCE—Would you be able to provide us with a list of the ones that would actually be undertaking some planning work with families involved with that service?

Dr Baker—Yes, I would be able to do that. It would depend upon their willingness to be named, but I am sure many of them would be willing to assist the committee.

Senator BOYCE—Off the top of your head would you have any sense about whether it is a handful or a substantial number?

Dr Baker—I think a substantial number are involved in developing plans for their clients. That is part of the approach that they take, and it is required by the standards they adhere to. In many cases we are talking I suppose about family situations, where ageing carers have reached a stage where they cannot continue to be a primary carer any longer, so there is now a need to look for, say, long-term accommodation options as an alternative. I am sure service providers are involved in that, but, as you are aware, there is a waiting list; the availability of long-term accommodation options is very limited.

Senator BOYCE—It has been said that you can have wonderful accommodation, you can have vast amounts of money, you can have great paid services available, but if you do not have people who care about the quality of all that or about you as an individual, you are still very open to abuse and exploitation. Would sustainability be one of the serious issues that parents are concerned about in terms of developing a plan?

Dr Baker—Yes, I think that is a key part of giving them a sense of certainty about the future, that any plan is sustainable—sustainable not in the sense of never changing but sustainable in the sense that as the needs, the aspirations, of a son or daughter evolve the plan will evolve too.

Senator BOYCE—You spoke at one stage about people with sensory impairment, either lifelong or people who acquire a sensory loss because of ageing, as requiring different service responses. Could you flesh out what you mean by that.

Dr Baker—I guess in both cases of sensory loss, whether it occurs early in life or later in life, what makes a huge difference to that person's ongoing independence is whether they get an early intervention service that can provide them with orientation and mobility skills and communication skills as well. If that early intervention does not happen, then often you are setting that person up for a high degree of dependence for the remainder of their life. One of the perverse features of the current system is that its investment in early intervention is relatively small compared to crisis management. But in these cases, as in many other cases, early intervention is the most effective and efficient response.

Senator BOYCE—I asked FaHCSIA earlier about what was going to happen with the age pension age moving out to 67. They will come back to the committee with some information on that. Obviously, it will affect a lot of entitlements other than simply whether you are on DSP or the age pension. In your report you refer to the Institute of Health and Welfare saying that the ageing process often begins at earlier ages for people with disabilities and that people can then develop not only disability related needs but age related needs. Can you talk a little about that?

Dr Baker—An example might be a person with Down syndrome who can acquire dementia at relatively early ages—dementia that is normally associated with an older age group. There are other examples as well. It is not a particularly satisfactory term but 'premature ageing' is often the term that is used for people who acquire health conditions at a relatively early age, and that seems to happen with certain disability groups. The policy response to that really should be that a person with disability who requires ongoing disability service support should also have access to aged-care support at the age at which they acquire an age related health condition. The system does not allow that particularly well. For example, there was a commitment prior to the 2007 election which NDS strongly fought for to allow people in group homes that are funded by state governments to have access aged community care services, which they have been denied. That still has not been enacted. In some ways, it has been overtaken by the health agreement around the Home and Community Care program. But it seems to me to be an example of how poorly the aged-care system and the disability service system work in coordination.

Senator BOYCE—Given that most aged-care assistance is based on your age or being over 65, should there be an earlier cut-off point for people with a disability? How should that happen?

Dr Baker—It is difficult to apply an across-the-board rule but there are precedents—for example, in recognising that Indigenous people develop age related health conditions at a younger age—

Senator BOYCE—And have a shorter life expectancy.

Dr Baker—Yes. There does need to be a policy response.

CHAIR—Do you think the insurance scheme will, to a certain extent, deal with this? It seems arbitrary and that is why I asked earlier about the 65 mark. Surely we should be providing for meet people's needs regardless of whether they have an age related or disability related issue.

Dr Baker—Yes, I absolutely agree with that. Any age is arbitrary and will not apply well to all people. The pragmatic difficulty facing the national disability insurance scheme idea is that, if we simply say that a person should receive the support they need regardless of age, which I think is the right position philosophically, we are essentially trying to take on reform of the aged-care system at the same time as reform of the disability service system, and my fear is that that will set back disability reform by 20 years. It is just too much to bite off in one chunk. So, in the longer term, I think the position you put is right, but in the short term I think we need to be pragmatic and say that the current population of eligible people under the National Disability Agreement, which essentially is those people who acquire a severe or profound disability before the age of 65, is a very poorly serviced population. As the first stage, my view would be that we should get a decent level of services to that population and then think about expanding the scheme.

CHAIR—I understand your point around reform of the aged-care system, but it is generally recognised that somebody with a disability is highly likely to need age related support earlier. If, in the same way as we have acknowledged that for Aboriginal people, we acknowledge that for those living with a disability, could there be some way of incorporating that into disability insurance—some sort of NDIS?

Dr Baker—Yes, there could be. There could be a system by which aged-care services are purchased for people with disability who have that related need earlier.

CHAIR—Thank you. Sorry, Senator Boyce.

Senator BOYCE—That is fine. I just want to pick up on one particular point that you made that I had not really thought about before. You point out that health screening and promotion activities for people with disabilities are perhaps less used than they should be because often programs are linked to the electoral roll, yet people with disabilities often are not on the electoral roll. Do you have any sense of the quantity that we are talking about there and of what the solution is?

Dr Baker—I think the broader underlying problem is that people with disability fare poorly in terms of health outcomes.

Senator BOYCE—Yes. But until we measure it—

Dr Baker—Yes, until we know about it, we will not do anything about it. Until we measure it, we will not do anything about it. I am sure it would not be difficult to find a way of getting better health services to people with disability. There is a proposal from the NSW Council for Intellectual Disability to develop a network of providers who have a speciality in providing health services to people with intellectual disability. There is the establishment of Medicare Locals, which is under consultation at present. The concept of the Medicare local is a linking up of services that can be used to try to get better recognition of the needs of people with disability. But I think at every stage of the health system, from health promotion through to acute care, the health system needs to be more responsive to the needs of people with disability. Unfortunately, historically, for very good reason, disability dissociated itself from the medical model of disability. I think that was for very good reason, but one of the by-products of that, I suspect, is that the disability service system has become disconnected from the health system. That has meant that people with disability are, as I said, achieving much poorer health outcomes than they should be.

Senator FURNER—I will start with some of the comments you have made in your submissions regarding some failures, starting with your comment on being under-resourced. The department indicated earlier this morning in their evidence on the NDA the quantum and delivery on the amount that is being projected for the NDA. You indicate that it is under-resourced. To what extent would you consider that it is under-resourced? You also indicate that there is inequity in the process. Can you explain what parts of the program are inequitable. Also, you indicate that it is difficult to navigate. Can you identify those issues for us as well, please.

Dr Baker—The National Disability Agreement has involved an injection of increased funding into the system, but it is not sufficient funding to keep up with the growth in demand. The Disability Investment Group did a careful analysis of this and produced a report at the end of 2009, and its finding was that funding, on average, was growing at about five per cent and demand and need for services was growing at about 7½ per cent per annum. So there is a gap of about 2½ per cent, which is growing year on year. Under current arrangements, it seems that that gap simply cannot be bridged. It will simply grow wider. It is propelled not just by ageing of population and population growth but also by some of the factors that have been discussed this morning, such as the willingness of parents to be sole, dedicated, lifelong carers for their son or daughter rather than having the expectation that the son or daughter will live independently under other arrangements when they reach 20, 30 or some other age. So social expectations are changing, and that is also driving demand for services. The gap is, as I said, substantial and growing, and I think there are many people now of the view that the current system is therefore unsustainable, so there needs to be a fundamental change in the way in which the funding is provided.

The inequity is apparent in many respects. It is apparent in the different levels of service funding and provision across states and territories. It is apparent in the different eligibility criteria and levels of support for different programs. It means that two people with similar levels of disability and need for support in different circumstances do not get the same level of support. Again I think that, although there is a move in the National Disability Agreement toward national consistency and establishing common rules across the country, this is a pretty slow work in progress, and ultimately equity will not be achieved without having a common, consistent set of eligibility rules and common entitlements across the country.

The third issue you raised, I think, was the complexity of the current system. Even for someone in my position who makes a full-time job of knowing the disability service system, it is still very complicated. I cannot imagine how family carers, people with disability and even service providers find their way around the current system. The eligibility criteria are complicated, pathways between service types often end up as dead ends and the articulation between different programs and service systems and between state and federal programs is poor. This essentially generates, I think, both risk aversion and bewilderment on the part of family carers. They do not feel empowered by this system. It is too complicated. They feel risk-averse because they feel that if they, for example, encourage a son or daughter to try employment and employment does not work out then they may be left with nothing or they may be at the back of the queue. The complexity is a product of the highly rationed funding. A lot of the administrative effort within state and federal departments goes into refining the rationing rules and building the gateways rather than looking at ways in which pathways and access to services can be opened up.

Senator FURNER—In response to all that feedback, looking at eligibility, how would you see that operating differently? Would it be a case of it being applied more generally? What areas would you identify?

Dr Baker—As I said earlier, what is sometimes called the potential population or the target population for the National Disability Agreement, which is people with severe or profound disability acquired before age 65, should essentially be the eligible group. At present, eligibility is simply eligibility to sit on a waiting list. My view is that, once a person is eligible for support services, they should be eligible for life, so that should continue right past the age of 65, with the understanding that their needs may change as they age, as they enter new life stages, their aspirations will change and the service response or their entitlement should change. As I think I mentioned earlier, this will also lead to people being willing to make more adventurous choices. So they may be willing to do without intensive services for a time because they do not need them with the knowledge that, when they do need them again, it will not be a question of having to wait in a long queue; they will be entitled to them.

Senator FURNER—We questioned the department this morning about their booklet *Planning for the future: people with disability*. Have your 700 members found that of assistance?

Dr Baker—Yes, I think it has been a helpful resource. Alone, it is not sufficient. People need an advice service because the range of things family carers need to consider are quite complex and do include financial and legal considerations, as well as trying to work out an appropriate sustainable service response. I would have thought that special disability trusts alone are very difficult for ordinary people to understand. Again, although I think the changes that have already been made and the further ones that have been flagged are all good and are all in the right direction, you can see the way in which special disability trusts were initially created, with very tight boundaries and very complex entry requirements.

Senator FURNER—Interestingly, you touched on that, because we also questioned the department on that. They indicated, from memory, that around 500 people expressed an interest in them and there had been an increase in the uptake of them. Do you think that one of the main reasons why there are some impediments around the uptake is as a result of the difficulty in understanding the complexities around SDTs?

Dr Baker—Yes, I think both the complexity and just the very tight, narrow definitions of the uses of the funds, restrictions on work and the tax effects and so on really made it a very restrictive initiative initially.

Senator FURNER—Thank you.

Senator BOYCE—You mentioned here about workers with disabilities retiring from the workforce, and this was an issue that was first raised with me about five years ago by the CEO of Endeavour. It was not something I had thought about previously. Could you just talk a little bit about how that situation may be different from the average Australian worker without a disability who waits until their super is looking as though it will keep them going or reaches age 65 and is eligible for the pension?

Dr Baker—Within supported employment, or Australian disability enterprises as they are now called, there are about 20,000 such workers and their profile is certainly ageing. About 75 per cent of them have an intellectual disability and all of them are there working in an environment where they really cannot work without support. They require the presence of support in order to work, and the vast majority of them could not maintain employment in the open workforce.

The issue of retirement has been growing to some years and, really, the government’s response to it has been quite inadequate. None of us, I suppose, when we get to retirement age, probably cope with change all that well, but for a supported employee I think the challenge is huge. People with intellectual disability need to approach change in a very measured, staged way, and most of them in the supported employment workforce do not have any other support options during the day. If they left the Australian disability enterprise they would be left without any support at all, and those that do have access to perhaps a day service, the day service has been tailored around people of a much younger age group. So there is not age appropriate day support for these people to go to. So many of them are at an age where they want to retire, their productivity has diminished very substantially, but they really are stuck within the Australian disability enterprise because they have nowhere else to go.

There I think some good responses to this around Australia that have been patched together by service providers in a sense in desperation about wanting to do something to this group. The best of them have a case management function built into them. It is not just a matter of saying farewell to a supported employee; they need to have someone there to help manage the change, and they all have a service at the other end which is an age-appropriate day support service. I think there is no doubt that we know how to respond to this issue in service practice terms. The government has announced yet three more pilot projects in this area. We really are at a point now where we have got the knowledge to have a national programmatic response, but we do not have government support to do that.

Senator BOYCE—Could you list those pilot projects?

Dr Baker—I could send you a list.

Senator BOYCE—Thank you. Are they federal government funded?

Dr Baker—They are. One is in the ACT, one is in Victoria and one is in New South Wales.

Senator BOYCE—Would the majority of people working either in ADEs or in open employment who have an intellectual disability be seeking to retire before 65?

Dr Baker—Yes, I think that is true. Many people with an intellectual disability, again, experience age-related conditions prematurely and their productivity diminishes quite dramatically at an earlier age.

Senator BOYCE—Would this be true for people with physical disabilities working in ADEs?

Dr Baker—Some types of physical disability as well, such as cerebral palsy.

Senator BOYCE—Yes, which would affect the body’s ability to cope.

Dr Baker—Yes.

Senator BOYCE—You might like to comment on research that suggests that, particularly for people with intellectual disabilities, their workplaces are almost their only social networking place as well as and therefore to move out of your job is to lose your friendship base as well.

Dr Baker—Yes. Again, you are quite right. That is a key consideration—that work, to a high degree, is the source of social networking, friendship, social status and social recognition for the people who work there. The risk for them about leaving work—and the reason for their resistance, understandably—is that they will lose all that social recognition.

CHAIR—Thank you very much. I know you have undertaken to provide a couple of things. It would be appreciated if you could.

Dr Baker—Yes. Thank you very much.

[11.31 am]

HUGHES, Mrs Joan, Chief Executive Officer, Carers Australia

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you, I understand. If you would like to see a copy of that, there is a copy on hand, although I know that, like our previous witnesses, you have been here a number of times before, so you should know the procedure. We have your submission; it is No. 39. I invite you to make an opening statement and then we will ask you some questions.

Mrs Hughes—Good morning, everyone. Today I am here really to address some of the issues regarding ageing parents of ageing people with disabilities. As you know from the submission that we sent to you, we believe that, along with the need to address the uncertainty and difficulty facing many unpaid family carers who are themselves ageing and the need for our society to provide suitable and well-planned care for people with disabilities, there must be also recognition of support to family carers to help them to plan for their own future and the future of those whom they care for. That was the focus of our submission and will be the focus of this opening address.

As you know, Carers Australia is the national peak body representing the diversity of Australians who provide care for people with disabilities: mental conditions, including mental health issues; chronic conditions; those in a palliative care situation; and those people who are frail. It is important to look at the statistics of the people that we are talking about today. I draw these from two sources: the ABS and Access Economics. Importantly, the ABS is just about to release some new data, through the Survey of Disability, Ageing and Carers. That will be new information, I guess, for this committee to look at. The important message to you is that the number of carers has increased.

Some commissioned research that we have just carried out with Access Economics shows that we now have close to three million family carers across this nation and, if we had to provide the support and care that they provide their family members and friends, the cost to the community and governments would be close to $42 billion each year. For this particular submission, it is important to note that we have close to 400,000 people who provide care for someone living in their household that is covered by this inquiry. Importantly, the two most common scenarios are of older carers who are caring for sons and daughters with disabilities, including psychiatric disabilities, and older carers caring for spouses or partners with dementia, chronic conditions, disabilities resulting from ageing or those in a palliative care situation.

Carers Australia believes that the policy and program developments that encourage ageing at home have really played a significant part in the solutions for care provision in our communities, but of course, as you know from the work that Carers Australia does, this cannot be at the detriment of the carers' own health and wellbeing and their choices in order to have a quality of life. It must be acknowledged that this has placed increased demand on family carers, who are still responsible for the majority of care provided in our communities.

Supporting carers as they age includes providing them with viable options for alternative care and support. All unpaid family carers need peace of mind about the future of their family members or friends once they are no longer able to provide care for them.

I have had the privilege in the last two weeks as part of a contract with the government to develop the national carers' strategy and to talk to many carers face to face. I would have to say that many carers of even young children have the legitimate concern that others would not be able to provide care to the same level because of their intimate knowledge of the condition and the relationship to the person they care for. So it is vital that alternative forms of care are viable and able to meet the needs of people with disabilities. This in turn would reassure family carers that they have a real choice and that they do not have to continue to care as their own health and well-being deteriorates as it does for so many of us as we age.

In the carer consultations the key message that the carers wanted me to take to government were around messages of guilt, worry, uncertainty but absolute commitment still to their family member wanting to have the best options for them when they can no longer care.

Even with improved services, a lack of information when carers need to plan for the future is a significant issue. We still have levels of service provided and funded by tiers of governments and through different programs even at the federal level for carers. Often carers are so tired and cynical in a way that they just feel they cannot go through what they need to in order to find viable options. Often carers are not aware or informed of these options or what services are available and as such they do not have the capacity to plan.

Carers have consistently reported to us that searching for relevant information is very stressful to them. It is time consuming and sometimes it does not eventuate in clear options for how they will progress their future and for the people they are supporting. You can imagine how exhausting this process must be for them.

Information is the key piece of the future planning puzzle, and it cannot be expected that carers have the time and resources to seek this information out on their own. Carers Australia believes that every effort must be made to simplify this process and assist carers in having sufficient information to make informed choices for their futures and the people in their families.

We believe that a national planning information and resource guide that is designed specifically for carers would assist family carers to have confidence about making informed decisions for future care. The ability for carers to navigate this complex system varies from person to person. We know that family carers face increased social isolation, high levels of stress and additional financial costs, which we refer to as the costs of caring. They have increased inability to save and plan for retirement and have been found to have the lowest health and well-being of any group yet surveyed.

All of these factors must be taken into consideration in implementing new processes to support planning for people with disabilities. Carers need to make difficult decisions, and all of these factors increase the difficulties faced by carers in supporting those that they care for.

Some carers find that the biggest hurdle to future planning is thinking beyond their current situation and challenges. Many may need significant assistance, information or even counselling before they even begin to think long term and plan for the future. We find that more and more carers are wanting to access counselling, and yet those services are still limited in the supply factors.

Carers Australia believes that the following key supports should be funded by carers to assist carers as they age and to support ageing carers in decision making on behalf of those they care for where that is relevant—a national planning information guide for carers; planning workshops for family carers with a specific focus on future planning; assistance towards the financial and legal advice for carers; importantly, emotional and counselling support to assist carers with letting go and supporting them in the transition stages of planning and decision making; and of course additional respite hours to support the time they need to plan. In addition to these direct supports for carers there is currently insufficient support, as we know, for alternative accommodation and transport for people with disabilities, and improved funding in these areas is absolutely essential.

The quality of service delivery must also be improved, with a greater range of options for care that suits individual needs and circumstances. Many carers still find that alternatives to the care they provide are not flexible enough to meet their needs or the needs of the people in their families. We believe there is an ongoing need for increased investment in innovative supported housing models for adult children with disabilities, and this is in line with outcome 7(b) of the National Disability Agreement.

It should also be remembered that many ageing carers themselves face an uncertain financial future and this is a separate but related concern. Plans for alternative care may be put in place and their caring responsibilities shifted to the informal system, but often carers, after many years of caring, have been unable to participate in paid work and will be left without retirement savings. This is still a very significant area of unmet need for family carers. Carers Australia would like options for financial support introduced and we have been calling on successive governments for years to look at a superannuation scheme for family carers who have contributed so much to the cost of care in our society for so many years. We believe choice, access and availability of information and resources to assist decision making are the most important aspects in enabling family carers to plan for the future of people ageing with a disability.

We are pleased to note in the revised terms of reference of this inquiry that there have been increases in two aspects of the inquiry. We made our submission to the first terms of reference only but we do welcome the amendments. The changes in the terms of reference better reflect the concerns of carers as they age. The inclusion of continued quality of life is particularly relevant; however, we would like to see a greater focus on the health and wellbeing of carers themselves as well as those they care for. We do not think item (b) currently reflects this adequately.

The focus on the development of services is important and, as we know, the system is not currently meeting the needs of this group appropriately. Item (d) also directly reflects what we know too often to be the central concern for ageing parents: who else will care as they do when they pass away before the person they care for does or when they are unable to continue to care, due to the demands of ageing, for themselves?

Senator BOYCE—Did the figures you gave us on family care—that is, three million family carers and $42 million—come from the report you launched during National Carers Week?

Mrs Hughes—Yes, they did, and that report is available on our website or on the Access Economics website.

Senator BOYCE—I will follow up on just a couple of things. You spoke about families saying that counselling was important to them and that they were not able to access services. Do you have any information about the use of family relationship centres?

Mrs Hughes—I have statistics on the use of the National Carer Counselling Program. That program is funded through the National Respite for Carers Program of the Australian government Department of Health and Ageing. Currently that program is assisting around 0.3 per cent of the total carer population.

Senator BOYCE—What does 0.3 per cent equate to?

Mrs Hughes—It is currently assisting around 6,000 family carers.

Senator BOYCE—And that is because it is capped?

Mrs Hughes—That is because the program has not grown.

Senator BOYCE—The funding has not grown?

Mrs Hughes—The funding has not grown. It is capped at up to six sessions of counselling. Often we find that carers do not need that number; it just depends on what is happening in their own lives. But they can then re-present and get more counselling if it is required, and that is particularly important in the transitions of caring.

With regard to some of the family carers that we are talking about in this inquiry: I spoke to a carer in Cairns on Friday. She has been caring for her grandson for years. He has autism. She is ageing and she is getting things in place for him, but she broke down and said: ‘He has been my life and I have had to take him on in extreme circumstances. What I need is some counselling to help me through the next stages of my life.’ She hopes these stages are going to be very positive, she is highly resilient, but she said, ‘I’m finding it really hard to let go.’ I think if more counselling were available people could let go and look at some of the planning options for them and the people they support, but we cannot lose sight in this inquiry of the fact that carers are of course still very central to ageing people with disabilities.

Senator BOYCE—You are talking, almost, about co-dependence. Not only is there that sort of emotional co-dependence; often there is also financial co-dependence. I have been told about pensioner couples who have an adult child with a disability and, if the disability support pension is taken out of the family budget equation, the family would have difficulty surviving. Are you aware of this? Can you talk a little about that sort of trap?

Mrs Hughes—The problem we have with people who are in the Centrelink system is that, if they have been totally reliant on the Centrelink system, whether they are getting carer payments, carer allowances, disability support pensions, carer supplements—even if you add all of that, there is now a lot of debate in our communities around the levels of poverty that people are living in. We are talking about people who are just trying to manage their whole life on fairly minimal incomes. We have this group of people in the Centrelink system who are way behind, because that has been their main source of income and, as you would know, Senator, the cost of care is huge. Even if they get concessions for certain things, whether it is health care, access to therapies and so on, they cannot survive. If you take away one component of that Centrelink payment they will be in dire straits. You know how much those pensions are worth. Even though there have been very welcome increases to them, they are not keeping abreast with the cost of living or with what we call the cost of care. Therefore those people cannot access some of the quality services and the quality equipment and therapies—all the services that we know both the person and their family need. These people do not even think about the notion of early intervention or prevention; it is just a matter of survival.

Senator BOYCE—But would this not also mitigate against people perhaps suggesting an adult child with a disability move out when they are young rather than when they are older. I am not suggesting that is for—

Mrs Hughes—I think it is more complicated than that.

Senator BOYCE—Is it an element?

Mrs Hughes—It would be an element of the financial stress, absolutely, but you have to look at the broad care situations values base—what options have been available for the person with a disability and their families?—and, if there have not been adequate employment services, if that has not been adequate for the carers themselves, you have a very complex care situation. It is not only the finances; all of it is related. Of course, if you have paid work or supported employment, the options for people open up. If you do not have that, you are confined very much to those financial constraints, but it is more complicated than that, as you would be aware.

Senator BOYCE—You mentioned that parents who are carers were concerned about the sustainability of the care—'Who will care the way I do, because I understand their issues and I love them; no-one else will do that?' What suggestions would Carers Australia make about how you build that into a plan to support someone once their parents are dead or cannot care any longer?

Mrs Hughes—You have to start much earlier than what is happening at the moment. You have to be able to look at what I would call 'support options' at the various stages of people's lives. If you think about a child with a disability from birth and what they need right through to the end of their life—if you think about those transitions—often carers access services only for themselves and their person when a crisis happens or they can no longer care. I would have hoped that this inquiry would look back to what services can be in families and with families right from the point of diagnosis or accident or when life circumstances change. Now we have a crisis driven system where suddenly people say, 'You've got to let go,' but you cannot let go quickly if you have been caring for a person for a long time and you know the person well. So there is often a lot of conflict with families being able to recognise what I would call the transitions of life and caring so that services go in much more at 'this end' than at 'this end'. As I said, with regard to the carer consultations I am doing at the moment, parents of kids who are still very young or in their teenage years and who are strong advocates of their kids think in the here and now. They know what they need, and how to get it right, right now.

Senator BOYCE—I think, though, that within the general population of Australia only a third of people have a will when they die. One of the reasons postulated for that is that people really do not want to think about the fact that they are going to die. How do you overcome what I suppose is a relatively natural aversion when you are talking to people who have a child with a disability about that early planning stage?

Mrs Hughes—That is interesting; it is a good question. Again, I was thinking about some of these parents I have met in your home state just recently. They are actually thinking about that more than the regular population is. These are strong carer and family advocates. They have been thinking about it, I think, from the very beginning, when their child was diagnosed or when something happened to that child and their family. They are very clear about what they think is needed for a quality care system, such as housing—and they always tell me that it is not just about bricks and mortar but about the care that takes place within the bricks and mortar as well. So I think there are many carers out there who are ahead of the regular population who are talking about death and dying, because it is such a reality for them. But, as I said, I think we need nationally to have these planning workshops where carers can really explore some of those hard issues. They have done that through the National Carer consultations—coming in, feeling so stressed about their life and the options for the people in their family that they are very willing to sit down and talk with people who know how they can get that system in place. It is important to do it a lot earlier, rather than what we have now, with people in their 70s and 80s wondering what is going to happen.

Senator BOYCE—This morning I asked FaHCSIA whether the long-term objective is to end up with a normal sort of life path whereby Australians grow up with their family, move out some time between the ages of 18 and, these days, 40 years into a household of their own choice and then make decisions about their own household, depending on their abilities and whatever, and perhaps even moving to a retirement village at the end of it all.

Mrs Hughes—I think it depends on the level of need. This is one issue we have with the ageing of the family carers and the ageing of people with disabilities. We have a much more complex family and care situation. In generations gone by, a lot of these people would not have survived past a certain age.

Senator BOYCE—They predeceased their parents in many cases.

Mrs Hughes—That is right. So the parents are living longer, and so are the people with disabilities. And you absolutely want those transitions of life and care to be the same as for regular Australians. But we find now that, where that has been made available for people as they are ageing themselves, often the services are not there at this end and they are actually coming back home. That is not really a viable option either—coming back home to ageing parents because of something that has broken down in the system.

Senator BOYCE—Perhaps they have been in supported accommodation or worked in an ADE and then retired and have had to come back home—is that the sort of thing you are talking about? Can you give us some examples?

Mrs Hughes—Or maybe they have had complicated health problems and the housing or the supported accommodation has not been a safe environment, sometimes, for them to be looked after in. I think that is a big issue for governments as well, as our health needs get more complicated because of disability.

Senator BOYCE—Would you like to comment a little on the differences in planning for someone with a mental illness or a psychiatric disability? For example, it might be an episodic problem rather than an ongoing issue.

Mrs Hughes—There is a pretty simple solution here: to make sure that those planning options are implemented when the person is feeling well. Often parents know that particularly well, or partners know that well. It is going to be a really important transformation that we are in around the progress of the National Disability Strategy and the National Carer Strategy. A lot of strategies put the person and their family at the centre of policy and programs. The Carer Recognition Bill says that carers now have to be acknowledged for their expertise. Often, carers of people with psychiatric illnesses are not factored into that. Suddenly, decisions are made here, they find out about it and they know that it is not right. I hate making generalisations, but in this particular group it is to make sure that the families are integrated into some of those conversations that are happening and that their expertise is acknowledged and to make sure that providers are doing it when they know the person is well. I do not believe that that is all that difficult.

Senator BOYCE—Mrs Hughes, you have suggested that Carers Australia would be well placed to do a program that would, hopefully, cut through the fog of programs and policies and provide information. Can you, (a), flesh out how you would see that working and, (b), tell us why you think Carers Australia might be better at doing this rather than an organisation like Centrelink or Medicare, or someone else who currently has a large database in this area anyway?

Mrs Hughes—When I say carers Australia I mean the carers associations—obviously, we work in a federated structure. The carers associations now operate out of over 60 sites across the country. They are, really, the only organisations that are very carer focused; that is their reason for being. Their database would not be as large as that of Centrelink or Medicare but, in terms of a specialised service and the reputation they have in the community, carers are now realising: ‘Yes, I actually am a carer. I am doing something extra and I need to talk, too.’ That talking is often with a carers support group or the carers association in the state or territory. I believe they have built up a very good reputation within communities and within the states and territories. Once carers actually identify as such, the carers associations can put them in touch with a whole range of services. Their specialty is around the family carer but they have very good connections with a whole lot of other providers. If they cannot provide the service, they can put people onto the right pathway to those services. So they often act as a bit of a clearing house or central point for that.

In terms of people feeling like they are connected to an organisation it is about ‘my needs’, but that does not negate that we do work with a whole range of other disability and mental health services and so on where that is their specialty. I think people often come to a service through something like being a carer and, therefore, the pathways are a lot easier. Also, I think you get national coverage and national consistency if things have gone through a specialty service. They already have systems of information set up around some of these planning options. It would be building on that and working with legal and other relevant expertise.

Senator BOYCE—So would you see yourself as providing information or offering planning services?

Mrs Hughes—I would say both. People have to come in and say, ‘This is something that I need to start thinking about,’ and then the associations can, with funding, deliver those workshops. They are already doing some education and training of carers. We are calling on the government to look at that as needing to be a national program. If carers are coming in and you are talking about how to be a carer and looking at the skills needed in order to provide appropriate care, why would you not do a module on future planning? It seems very sensible to me. If carers are coming in and doing training on, say, the safe use of medications, where we can get support, where the services are or how I can advocate better, it seems to me that this would be a great link to that, and you would have a workshop for those people, where that is relevant, on future planning.

Senator BOYCE—So are you teaching future planning; are you actually assisting people with a plan?

Mrs Hughes—Both, I would think. It depends on the knowledge of the carer, and that varies. Some people might have done a bit of work in this area and some people will know a bit about the special disability trusts, but others will know nothing. Again, you would tailor make that according to the information needs of the carers and you would pull experts in to talk about the various planning options. You would want carers to leave with a plan and you would want them to lodge that plan with the various authorities. But people need time to sit down and work that through. Often carers can do it in the safe environment of being with other carers in similar situations, so for the learning, even though it might be facilitated by, say, a carers association, they would bring experts in according to what knowledge was required.

Senator BOYCE—It has been suggested that there could be a conflict of interest between service providers providing planning services, because they may be more inclined to promote their own services as part of the plan, and having planning as a stand-alone system. Would you comment on that.

Mrs Hughes—I do not see that there would be a conflict of interest. If the carers associations were putting carers in touch with, say, counselling services, it is not a conflict of interest if they are providing that service, because that provides easy access. But, if people were helping people to do wills, trusts and all those sorts of things, that is not a conflict of interest because you would be getting expertise in around that. There would be a few circumstances where that would be the case, but I do not imagine that is to the detriment of the carer themselves, because you want to make it as easy as possible. If you are identifying that emotional support as absolutely essential, and the carers associations are delivering some of that, that is fine, but they may not be and they might refer them to another sort of counsellor. So I do not see that as a conflict.

Senator BOYCE—Thank you.

Senator FURNER—Returning to the subject of information, I congratulate you on receiving funding from the Department of Health and Ageing for the development of a website. Would you inform the committee of the stage you are at in that development process.

Mrs Hughes—We have had some issues with websites, as you do. We had this dream of getting nine websites into one and there is some difficulty with that because the states and territories have different levels of information depending on their jurisdictions. But it is up and running and is at the stage now where people can access a whole lot of different policy documents, and it links to the state and territory carers associations. Some of them have decided to revamp it slightly, which is mostly due to their membership base and whether they want to take donations and those sorts of things. We have what we would call a bit of a hybrid at the moment.

Senator FURNER—What is the accessibility to the website? Is it for members of your organisation or for carers in general?

Mrs Hughes—It is really for the general public. At the Carers Australia level there are obviously a lot of policy documents on the site, so that is suitable sometimes for people doing research or for students, but also for carers themselves if they are interested to know what Access Economics has just said about caring. The needs of the states and territories are slightly different because of their large membership base, whereas our members are the state and territory carers associations.

Senator FURNER—So it is a fully functional website; it is not a work in progress?

Mrs Hughes—I think websites will always be a work in progress, absolutely. At the moment we are trying to look at ways to combine what I would call two versions of the website into one. So, if the states and territories are looking at their own needs, they will still be links to the state and territory carers associations. If you go to the home page, you will still see links to all of the state and territory carers associations. That is up and running at the moment.

Senator FURNER—Page 4 of your submission lists seven dot points relating to resources that would provide information on a range of issues. Are those services currently on the website or is that an ambition for the future?

Mrs Hughes—At the moment a lot of this information appears in hard copy and some of that has been transported to the website. An information kit has been funded through the Department of Health and ageing and FaHCSIA has done some work as well. There is information around the financial issues of caring—filling out wills and those sorts of things. Again, it depends on whether the legal responsibility sits with state and territory governments and/or the federal government. We have a young carers website; that is being upgraded at the moment as well. It is a work in progress.

Senator FURNER—You raised a number of issues in terms of requirements for rural and remote Australia. I could suggest that the NBN will cover that all for you and you will be safe in the hands of the government in providing adequate access to remote areas. Are there genuine concerns about the remoteness of some of the carers and their not having access to the website? Is that why that is there?

Mrs Hughes—It is a policy that we adhere to. That is one way that people get information. What you have to remember is that, as I said, we have millions of family carers accessing information in different ways. The broadband, of course, will assist to a point, but you have to have things available in hard copy. You still have to be able to post things to some carers, because that is the way they get the information, and you still have to have a phone services. As to the magic idea that everyone will access it, of course now and into the future that will be the way with some carer populations, but if we are true to our principle that we have to provide information in all sorts of formats then we would do that, and we would still do that, no matter that the national broadband were up and running and the world had changed. There would still be people who have to get the information in different ways. Often that means walking them through in a workshop setting or over the phone. There are other ways in which people will action the information, not just by sitting at a computer.

Senator FURNER—You also raised the need for cultural and linguistic diversity. Could you go to the issues associated with that, please?

Mrs Hughes—Under previous governments there were commitments in terms of translating basic information and having interpreter services. I believe that that has eroded over time through lack of funding. We have a long way to go until we get back to the notion that we live in a very diverse land and that we need to make sure that, no matter where people come from culturally, the information is available to them in different formats and different languages. It is not just about language; it is about having someone in their culture that they trust being able to walk them through some of the options—in this case, for service provision. When I first started working for carers associations nearly 20 years ago, we would have a whole range of different information resources translated. That has eroded over time. I believe that it is appalling because we have more and more people whose needs are even more complicated when English is not their first language. I would have thought that, if we adhere to the principle of diversity and quality, it would not really matter where people were born. If they are living in this country they should have access to those basic services, like information that is translated for them. As I said, if they cannot use that, then they should have people in their own culture or people they trust walking them through what might be available to them.

CHAIR—I want to go back to the issue that Senator Boyce raised around conflict of interest. The other conflict of interest that comes up, as you would be aware, is around what is in the best interests of the person with a disability and, sometimes, their carers. As I understand it, what you are suggesting is that you provide counselling and planning options for carers, but the person with a disability should be able to access other services to enable them to plan, if they so wish. Obviously, carers would want to be involved in that and the person with a disability would probably want their carer involved, but would you see it as essential that the person with a disability can access separate services if they so choose?

Mrs Hughes—A lot of that comes down to the initial entry and assessment process. If you think about the experiences that you might have had with medical providers and so on, often there is so much focus on the patient. We still have that, in a sense, within community care and the broader aged and disability systems. I would hope that, with all the new reform, where people are talking about the person and the family—looking at people centred care—that it starts from the very point of assessment. If it is determined that all of these things need to happen for the person and the family at that entry point, at the time of assessment, and the assessment is comprehensive and about whole of care and whole of family, then you will have different pathways according to what comes out of the assessment. Sometimes it would be for them together and sometimes it would be separate. What we have now is too many systems. They do not join up. The problem is that, as people get into it, it still has not been sorted out. So I think that what I would call people centred care and a whole-of-family assessment process would help.

CHAIR—My other question relates to a point you made earlier. Senator Boyce asked about the use of the new program under the family relationship services and centres, and you knew about the DoHA program but not the FaHCSIA program. I am wondering if that means that the FaHCSIA program is not raising awareness of the program sufficiently.

Mrs Hughes—I do not think so. I have spoken at their conferences and taken carers along with me and have worked with that organisation to see where—I do not think it is duplication—we can work better together. As you are aware, we have some carer support in FaHCSIA, we have a lot of it in DoHA at the federal level and we have the whole Centrelink system. I do not know who can join these dots—is it PM&C? Do you know what I am saying? It is like we have these—

Senator BOYCE—They have regular meetings—they said so this morning.

Mrs Hughes—It is very important for people because the system has become very complex. I think even at a government level there has to be much more connection with the different programs, portfolios and ministers to see how we can, I suppose, join the dots and not duplicate. I do not believe there is a lot of duplication, but I do believe that some of that integration has not happened, in a policy sense.

CHAIR—I was not meaning to imply that there was duplication. There is a review of the family relationship services and centres. Basically, the program has been done and is about to be released—this morning the department said 'soon'. So that might provide useful information for you. My concern was more that you are the major or peak organisation for carers across Australia and yet—I am trying to say this so that it is not a criticism because I do not mean it as a criticism—one service is being provided that does not seem to be as high profile or perhaps on people's radar through the family relationship centres. This seems to me to be a bit of a concern because they provide counselling services as well. It seems to me that that service should be integrated with all the other services that you have just been talking about.

Mrs Hughes—Sometimes those decisions by governments are not based on too much at all. A need is identified and sometimes those decisions, I think, are so slow but sometimes they are too quick as well because they have not looked at what infrastructure is already in place. So now we do not have enough services, as we know, but we have many providers, especially in the carers' space. You want a lot of options but you also do want that coordinated at some point. I think that is the problem. We also have the identification of carers as an issue that we have fought very hard for, as an important step to say, 'Actually, I do need some support here.' Suddenly, you think, 'Well, this has happened over here,' but the government has not spoken to Carers Australia at a policy level about that. I think sometimes those decisions are not often well informed by the experts who have been working in this area for a long time.

Senator BOYCE—You would be aware that there is a lot of small organisations doing a range of interesting things in this sort of long-term planning space. Is the association aware of Microboards being established around individuals as one way of dealing with this and, if so, the views thereon?

Mrs Hughes—No, but I could check with my members.

Senator BOYCE—The department this morning told me they have done a stocktake of organisations that are providing planning support, and that it will be released soon.

Mrs Hughes—We know about that and one of our members is involved in that. But, again, this is one of those coordinated approaches that needs to happen with what is happening in the FaHCSIA world and what is happening in the DoHA world. In the DoHA world there is a program for older carers of older people with a dementia focus, and they should be looking at some of the learnings of that delivery of service. We know about these things, but Carers Australia is also a very small organisation. We try to keep our finger on the pulse of all of the things happening at the government level, but sometimes, not always, because they are under pressure, they go off and make decisions and, as I said before, they do not bring the experts in to see whether there is an infrastructure that can be built on rather than starting again.

CHAIR—Thank you very much. As usual, your evidence is very much appreciated and valued.

Proceedings suspended from 12.16 pm to 1.16 pm

HECKENDORF, Mr David, Private capacity

CHAIR—Welcome. We are recommencing our inquiry into planning options for people ageing with a disability. I would like to welcome Mr David Heckendorf to today's hearing. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I also know that you know that, because you have appeared before. If you do want any further information, the secretary has that. We have your submission. Thank you very much. I invite you to make an opening statement and then we will ask you some questions. I know you know the ropes.

Mr Heckendorf—Thank you. I thought I would start by setting the scene. When I was five was taken from my family. My family was encouraged, I should say, to put me in an institution down in Sydney. They lived in the country. I was in the institution from the age of five up to approximately 22. I attended specialist schools for people with disabilities. When I reached 16 I was then encouraged to go into a sheltered workshop where I earned initially $3 for a 40-hour week. Initially I was working on a production line, but I was later moved into the computer area, where I was programming computer programs for the accountants' area and so forth. I used my computer skills to go to TAFE and do a certificate in computer programming. I then used that to gain entry into the University of New England, where I undertook my Bachelor of Arts degree.

Moving from an institutional environment into a university environment was scary at first because I had been looked after in an institution 24/7. Once I settled into the university environment, I found that other students got to know me and they were very helpful. Once they realised that I did not have two heads and did not need them to carry me, they started to socialise with me and invite me to parties and ask me if they could help me in different ways. It was a real eye-opener to me because when I was in the institution the only people I came into contact with were either paid staff or other residents.

This social interaction continued when I came to Canberra and I went to the law school down in Acton. I found that once I got settled in, once people started to know me, once I started answering sensible questions and the like, other students would ask me my name and start communicating with me. I would not have had that social contact if I had stayed in the institution because, as I said, I would not have had the same social interaction opportunities.

My wife and I both have what would be classified as profound disabilities—cerebral palsy. This means that we rely on a team of carers to come and help us possibly seven times a day, starting at six o'clock in the morning. The last shift finishes about 10 o'clock at night or 9.30, depending on what we are doing. There are times when we do not have anyone come and there are times when we value our own privacy. I work full time as a public servant in the Department of Health and Ageing but that is not who I am representing today, of course. I welcome any questions that the panel might have for me.

Senator BOYCE—Thank you, Mr Heckendorf, for coming along today. One thing that we always find difficult in these inquiries is to have the voices of the people with disabilities. It is good to have you here representing one group. The group we find the hardest to get to of course is the group with intellectual disabilities. To hear their voices is very difficult. Would you mind describing to us your current living situation? Are you and your wife living alone with carers coming and going?

Mr Heckendorf—Correct, yes. We get an individual support package from the ACT government, which is approximately $145,000 per year between us.

Senator BOYCE—You pay $145,000?

Mr Heckendorf—No, we receive from the ACT government a package of funding worth approximately $145,000 between us. My wife is a little more disabled than I am, so gets a greater proportion. We also receive some services from the HACC program via a local organisation called Home Help Service ACT. They come in and give me lunch at work and they come in the afternoon to help Jenni get up from her afternoon lie down.

Senator BOYCE—You talk about losing your parents. Mine are getting to the stage where that could happen too. What involvement do family and friends have in your life with emotional and other support? I include fun in emotional support.

Mr Heckendorf—They are critical. They are very important. We do not see our families on a day-to-day basis, but we communicate with them via the internet, via Facebook, via email, via telephones, and they visit two or three times a year. Jen's parents are from Sydney and mine are from Lithgow. We are in Canberra without any natural support whatsoever, so all our care must be provided by paid staff. We do have a small number of friends that we see from time to time. They might pop over every three or four weeks and say hello and so forth. I have work colleagues that I socialise with at work, but as far as our support goes, physical support, we do not have any natural nonpaid support at all.

Senator BOYCE—You have talked about the fact that your family is obviously getting older, as are you and your wife. What do you envisage that you are going to need in the future that you cannot currently access?

Mr Heckendorf—The level of support that we receive is quite expensive, as I said before, $145,000 between the two of us. Our disability is going to continue to reduce what we are able to do for ourselves—not because cerebral palsy is a degenerative disability, but rather because we use our bodies in awkward mannerisms and that puts stresses on our muscles and bones that the average person would not have to bear. The ageing process, if you like, is because of not using your body, in a sense. Because we are sitting down all day, we are not walking around so we have poor circulation and less muscle tone in the legs. Because I use a head pointer to do my typing, which enables me to work, I might get RSI in my neck at some stage.

Senator BOYCE—Is it simply that you will need more of the same services, or different services?

Mr Heckendorf—We will need more of the same but we will also need to have some social contact, and we will need assistance to get out into the community. Already my wife has been quite isolated in our own home, which we rent from the ACT government. We would like what you were talking about this morning: some kind of a retirement village type situation whereby we had our own little flat and garden and so forth but be able to participate in some kind of common area or dining room.

The reason I explained my early years to begin with is that I know what institutions are like. I have lived in rooms for 20 years where we did not even have a curtain between beds. We had 25 severely disabled persons sharing three toilets. Looking back, that situation was really appalling so I am not in favour of institutions per se. But even little group homes can be institutions in their own right, because it is not the building that makes the institution, although that has a lot of influence over it; it is more about how it is run. It is more about whether the residents have a say in the rules that apply. It is about how much choice you get; it is about how much private time you have for yourself and whether you can have visitors come and go and sleep overnight. It is those types of choices that make the difference in an institution—the quality of life, the living situation. Many of our friends are in group homes and, in some ways, they are more isolated than we were back in the institution. Back in the institution, if we did not want to talk to someone we could go and talk to someone else or get away from them, whereas, if you are in a group home with four or five people, you had better get along with them because they are going to be there for a long time. While choice of where to live is part of the rhetoric, the practicalities are that unless there is another spot for you somewhere you are stuck with where you are.

Senator BOYCE—And what is the likelihood of there being another spot somewhere else?

Mr Heckendorf—Exactly. We heard this morning about waiting lists and so forth. I think the waiting lists are very understated because there would be people who have not even put their names on the waiting lists because they think, why bother? They are never going to get one anyway so why bother putting your name on the waiting list? What I am interested in is using community resources that are available to everyone and requiring them to be more inclusive of people with disabilities.

My wife and I live in our own government house because we put our name down for public housing when we first came to Canberra. It was not because the agency that was providing our care suggested we do so. It was because that is what people did when they needed somewhere to live and could not rent privately. While renting privately comes to mind, I would like to say that Jenni and I are unable to purchase our own home or move from house to house as other people do. When you are young you might start off by buying a small bedsit and then, once you have got that paid off, you might go and buy a one-bedroom flat and then a two-bedroom house and you build your way up. If you have two wheelchairs, there is no way you can buy a bedsit. There is no way you can live in a two-bedroom unit on the second floor and so forth. So the entry into the private market for people like us has to be in a much higher price range than we can afford. The problem with that, again, is how long I can reasonably be expected to be in the workforce. It took me until I was 35 years of age to get a job in the Public Service. I have been in it for nearly 11 years but, if my neck develops RSI, then I could find myself next year being unable to type and unable to work. So how can I afford to run the risk of getting into a mortgage and doing the appropriate modifications to our house if I cannot be guaranteed a job for the length of the mortgage?

Senator BOYCE—Hopefully, the Productivity Commission might look at the tax treatment of some products and some of the needs of people with disabilities and work towards allowing people to build some sort of wealth. You mentioned the idea of a retirement village type of setting. Have you explored current retirement villages at all? Are you aware whether you and your wife would be eligible to move into a current retirement village and, if so, would you want to? I do not mean today but in 10 or 20 years time.

Mr Heckendorf—I have not researched it yet, because I think I am still a bit of a way off there.

Senator BOYCE—Would you see that as an overall solution?

Mr Heckendorf—There needs to be an intermediate stage of transition between disability on one hand and the aged care system on the other. There needs to be a 45 to 65, or 50 to 75, type of middle ground whereby the services that we receive are designed for that age group. Changing disability services would potentially overburden the disability sector in providing for younger people with disabilities. Changing the aged care system would again require the workforce in that group to reskill and involve other disability issues. I think there is an intermediate stage where we need a transition and a workforce that can be trained and services that can be provided that pick the eyes out of both systems and can draw on the resources of both systems to tailor the services needed for that 45- to 70-year-old age group. Coming back to your question, I am hoping that by the time we are looking to go into a retirement type situation a lot of the baby boomers may have already gone through—

Senator BOYCE—Not too far through, I hope.

Mr Heckendorf—and then we might benefit from their advocacy for improving the aged care system.

Senator BOYCE—As a baby boomer, I support advocacy by baby boomers. It is a very, very good thing. You are talking about new services, not necessary new service providers but different packages of services. Could you tell me whether you have experienced a service that was unsatisfactory—and I hope you haven't—but, if you have, have you had the opportunity to do something about it, or have you simply had to accept it because there was nothing else for you if you did not take it? Also, how would you go about complaining about unsatisfactory services?

Mr Heckendorf—I usually get on the board of management and advocate at that level. I am quite vocal and outspoken. I tend to do my homework before changing from one service to another. The point was made this morning about the idea of support packages and which services to go with. Some were illusionary—for instance, if there were no agencies to choose from, or if agencies looked at what was required and said, 'We don't have the staff that can provide you with that level of care.' At the moment, we have got four different agencies providing us with care. In the past, there have been as many as six or seven at one time. It can get to be a bit overwhelming.

Senator BOYCE—A bit like the mall in the middle of your lounge room.

Mr Heckendorf—That is right. Any notions of privacy go out the window rather quickly. Until quite recently we have chosen episode based services, meaning that they would come for a shift to do specific tasks and then leave again. Recently we changed to a more inclusive service that would provide us with a much more holistic type of care so that, if we want to go out on a Saturday night or go down to the coast for a weekend away, they are more likely to support us in that activity, rather than the services that only come in for a shift here and a shift there.

Senator BOYCE—That sounds very good in terms of your managing to organise it to meet your needs. Have you hired all these service agencies? Do you and your wife employ them yourselves or are they provided through a broker? How does it work?

Mr Heckendorf—We have one primary agency that both holds our ISP funding and provides probably 80 per cent of our service that we rely on.

Senator BOYCE—Is that a satisfactory arrangement for you?

Mr Heckendorf—At this time. I was also going to say we have two or three other agencies that we have had contact with over the years who continue to come in to provide care for us. They are paid for by HACC funding. It is not so much that our primary service coordinates with them; it is more that we have asked them to cooperate with each other so, if one could not cover a shift tonight, the other one might be able to cover it and not do tomorrow night instead.

Senator BOYCE—Does that happen without your having to make phone calls all the time? Is it relatively seamless now?

Mr Heckendorf—That is the result of having a much more institutional type service provider looking after us rather than a service provider that only provides a set type of service.

Senator BOYCE—You spoke before about how it was the people who create an institution or a home, irrespective of size and other things. What would you see that we would need as safeguards when we are talking about vulnerable people, not just people with physical disabilities—and obviously if you are articulate you are in a far better position—but also people with intellectual disabilities who may not be able to speak up for themselves? What would you see as the safeguards that would be needed to ensure that these places were homes not institutions, irrespective of the size, when the parents or carers are not around anymore?

Mr Heckendorf—I am a lawyer, so I have a legal background. Of course I am going to say that we need a federal disability act, picking up a lot of the issues around accountability and a code of ethics and so forth—not having the code of ethics embedded in the act but having it as subordinate legislation or policy so that the code of ethics can change from time to time. Legislation at the state level varies incredibly. In the Northern Territory and the ACT, the disability services acts are approximately seven sections long. Compare that to Queensland and Victoria’s very new pieces of legislation, which go to over 300 sections, covering a whole range of different issues and so forth.

Besides the legislation, we also need proper pay for the people that do the work. I am sorry to keep going on about the pay, as other people may have done or may do, but when you are paying a care worker $18 an hour—and they can get that for walking dogs or packing shelves and so forth—how are you going to expect them to do the appropriate training and have the appropriate commitment to the job? We often get 24 carers trying out for jobs before we get one good one that is suitable for the job, and then it is hardly enough money for them to base their career on, buy a house, move up in the rent market and so forth and live with an appropriate standard of living to encourage them to stay in the job. But there is also the message that you are sending to the community—that people with disabilities are only worth so much because the people that work for them are only getting a pittance in return for a very difficult task. I know that if I were not disabled I would not be wiping people’s bums for $18 an hour. It just is not sufficient.

Senator FURNER—Thank you, Mr Heckendorf, for coming along today. It is much appreciated. What was your employment prior to having commenced with the ACT government? I think you mentioned some type of employment. Could you elaborate on that again, please.

Mr Heckendorf—When I was 17 I was encouraged to go into a sheltered workshop, where I stayed for about five years before going to university in Armidale. In 1993 or 1994 I was involved with Disabled Peoples International, Australia, here in Canberra, for about 12 months. Then I went back to uni. In the beginning of 2000 I was with the Attorney-General’s Department. After eight months I went to the Department of Health and Ageing. In 2006 I got a senior policy position with the ACT government in the disability policy area. Earlier this year I came back to the Department of Health and Ageing.

Senator FURNER—You make the point in your submission about some of the enormous costs you have. One example is the replacement of your wheelchair every five years, which costs $20,000. That is quite an exorbitant expense that you have to deal with. You make suggestions about ways of reforming the disability support pension or the tax system. If we lived in a utopian world, how would you see those sorts of changes implemented?

Mr Heckendorf—People who are fortunate, such as me, who purchase a new wheelchair to get to work each day, should probably get tax deduction. If I could not have my wheelchair, I could not work. It is the same as people buying uniforms or laptops—it enables them to do their work. Does that answer the question?

Senator FURNER—Yes, it does. I see the comparison you are making between an employee having a tax deductible item for their employment and your type of employment needs. You go to some length to talk about your desire to move into housing, but there are limitations with housing such as not providing access to the homes. Do you think that either as a government or as a society we are improving on the conventions for disabled people in our society and recognising their needs?

Mr Heckendorf—As our population ages, more and more ageing people are going to wake up one day and say , ‘Oops, I can no longer live in my two-storey mansion. I’d better buy something on the ground floor. I can put a slight ramp in, but I can’t climb stairs every time I want to go to the loo.’ To answer your question, I do not think it is improving quickly enough. It has been 20 years since the enactment of the Disability Discrimination Act, which expressly excludes certain types of activities, mainly in private homes, so there is not the incentive for builders and developers to make the houses that they build wheelchair accessible or able to be made wheelchair accessible. There is a fear that if you are building a new house to sell tomorrow no-one will want to buy your new house because it does not look like a normal house, because the majority of the population do not need wheelchairs. By making it wheelchair accessible you run the risk of alienating a great proportion of the market.

CHAIR—I want to ask a specific question following up on the comment on tax deductibility for equipment. You make the point in your submission that the blind disability support pension is different from the broader disability support pension. It seems to me to be really strange that one group of people—

Senator BOYCE—'Historical' was the answer I got when I asked about that.

CHAIR—When you raised this with government, which you obviously have, what feedback did you get in terms of making it equitable?

Mr Heckendorf—None. I have raised this in a number of these forums, and I have got very little reply on that issue. I feel that the threshold to qualify for the blind pension is a lot easier to draw lines in the sand for than it is to qualify for the DSP. People with bad backs, for instance, might qualify for the DSP. I am certain you would not want to be advocating that level of disability. To qualify for this type of benefit I look more towards people with severe and profound lifelong disabilities. They have very little opportunity to build wealth in their own right. I think it is very unfair to penalise these people by having income and asset tests. Furthermore, if my parents are thinking about making a will and leaving the house to me or leaving it to my siblings, a common mistake is to think: if I leave it to David he will lose his pension. Furthermore, it is a common mistake that people in sheltered workshops are often told that they cannot be paid more than the minimum wage because, if they are, they will lose their pension. That is a misinterpretation of the law but, unfortunately, that is how the law gets interpreted, and we do not have the necessary complaints mechanism or knowledge to change those views.

Senator BOYCE—Currently, you or your wife would be ineligible for anyone to set up a special disability trust for?

Mr Heckendorf—That is correct. But if my parents leave a third of their wills to each of the siblings, why should my sister and brother enjoy their inheritance in whichever way they wish but I have to put mine into a DST in order to subsidise my care? To my thinking, that is discrimination.

Senator BOYCE—Yes, you might think that.

Mr Heckendorf—Yes.

CHAIR—Thank you, Mr Heckendorf. Your evidence has been really useful and valuable to us. If you think of anything else you would like to let us know, feel free to send us a supplementary submission. We always welcome supplementary submissions.

Mr Heckendorf—Thank you.

Senator BOYCE—Mr Heckendorf, we did not get around to asking you any questions about your idea for a centre of excellence for research. If you would like to put some of that in writing, covering how you would see that existing, how it would work and what it would do, that would good.

Mr Heckendorf—Yes. Thank you.

[2.07 pm]

FARROW, Mr Phillip John, General Manager, Government and Sector Relations, Bedford Group

CHAIR—Mr Farrow, welcome. I understand you have been given information on parliamentary privilege and the protection of witnesses. If you need any extra help, the secretariat has more. We have your submission, which is No. 29. If you would like to make an opening statement, we would welcome that, and after that we will ask you some questions.

Mr Farrow—Thank you for the opportunity to present before the committee. As you would have gathered, Bedford is one of South Australia’s best-known and most diverse services. We are currently providing services for some 3,000 people with a disability or disadvantage

Senator BOYCE—In South Australia only?

Mr Farrow—Yes, in South Australia, in both metropolitan and regional settings. We have a mixture of community and centre based activity so we have a broad spread of service delivery. We have approximately 800 people working in our ADE operations. There are about 160 residents living in our various forms of accommodation. We have about 80 people in a congregate—I will not say ‘institution’—setting in the foothills of Adelaide, and the remainder are in community settings. We have about a hundred people involved in our day options on vocational activities and about 1,900 involved in open employment and Job Services Australia programs.

As you will also have gathered, we have tried to draw on experiences and comments from a range of sources, including members of our family network. We hold meetings every few months with family members and carers. About 80 or 90 people on average turn up to those meetings, and they provide us with some useful insight into what is going on in the disability field. We were also involved in a bit of internal research when we were looking at some retirement options for people in our ADE workforce. As the committee is also aware from our submission, we have indicated that we believe the system needs significant reform. We particularly welcome the review by the Productivity Commission into long-term disability care and support and we have made a submission to that in our own right.

We have questions about whether or not the system is adequately resourced. The effectiveness of the interaction between the different portfolios and across jurisdictions is, we believe, problematic. It can be difficult to navigate—that is feedback we have received from various sources. There has been minimal attention afforded to planning. There have been a lot of crisis interventions and responses.

As our submission indicated, we believe there are a number of key broad government policy matters or principles that need to be considered. At times, some of the frameworks are, we believe, a bit questionable in terms of policy design. There are significant issues in terms of people being able to move across and in between jurisdictions—the interfaces between the portfolios gets a little bit murky at times. At times we find it a little bit frustrating that there is ‘the right’—one only—model of service delivery. It was interesting to hear some of the earlier presenters talking about the possibility of opportunities to move into retirement-style complexes or other options. We would support that. We believe there is a need for a review of government policy and for further debate about what those frameworks are.

We also recognise the importance of choice for the individual. That is one of the underlying principles upon which we try to develop all our services—that people do have the right to choose. We have also recognised the need within Bedford for change and so we have developed a far more holistic model that tries to cater for the diverse needs of people that come to our organisation. We try, in a sense, to provide a bit of a one stop shop. If it is a non-vocational service they are after, we might be able to help with that or refer them on. We might also be able to help with supported employment, open employment, accommodation in different forms and so forth.

As I mentioned, we think the interfaces between the federal and state programs and portfolios are nowhere near as robust and effective as we would like to see. We do see self-managed funding and a self-management approach as being very useful, but we do would add some cautionary notes in that we really need to make sure that that sort of approach is underpinned by true choice—I will qualify that later on—appropriate accountability and an accreditation system. The latter will ensure the quality and integrity of service delivery to clients is not compromised in any way, shape or form.

We are also conscious that there are various differing forms of assessment criteria and different funding levels across the different jurisdictions and programs. I have already touched on the fact that a number of our family members and carers have—and in our submission we talk about the one stop shop—difficulty in finding out where to go to access information about government programs. I refer in the submission to a state based web framework that the South Australian government has put together. It is in its formative stages. It has been around the place for a year or so, but it has to be developed a little more, in my opinion—it is not quite as user-friendly as it might be. It adopts a life stages approach, with five or six different groupings of people with disability—children, adolescents, adults, aged people and so forth—and it provides a series of linkages to different frameworks. Again I was interested to hear presenters—I think they were from Carers Australia—talking about some work they are doing on some information technology, portals and so forth.

On the subject of respite and retirement: earlier Dr Baker spoke about some of the issues with retirement options for ADEs. It is an issue that we are finding of significance for our workforce. I mentioned in our submission that we have a number of people who are moving into their forties and fifties. At least 10 per cent of our workforce are now in the 55+ age group and we have a total of about 40 or 45 per cent who are over 40. As they are moving into this transition-to-retirement stage, there are issues that we are having to confront. We are finding the same in our accommodation options in our Balyana complex in the foothills of Adelaide. About a quarter of our people are in their fifties and we have a handful over 65, so we are confronting some real issues in terms of that ageing and disability interface.

One of the issues for service providers relates to sector capacity. As we are finding that the demographic of our workforce and our clientele is changing, so too are the needs of our staff. There are issues with being able to attract, retain and develop people and, as we have a workforce and a clientele that is changing and ageing, we are finding that there are additional issues that they need to confront. The submission picks up on a number of other points, but at this stage I would be more than happy to take questions from the committee.

Senator BOYCE—You might like to start by telling us what you are doing about people who are moving into retirement. If anything, what can you currently do?

Mr Farrow—We have embarked on a number of things. Going back two years, we undertook an internal research project just to find out, particularly for our people in the ADE sector, what their expectations of retirement were, what did they understand it meant for them and what sort of changes they envisaged. It is fair to say that some of that information indicated that they really were not giving it that much thought. There was a group of people who largely thought that it would mean they would have a bit more free time for themselves and they might do a little bit of extra shopping. But largely they thought they would be continuing to do much of what they were doing now but they would have a little bit of extra time. There was an expectation amongst some of them that they would still be able to come to work to meet their friends because of the social interaction. That is one of the important roles that an ADE does play. It does provide some of those social frameworks.

Senator BOYCE—Sometimes the only social frameworks outside family.

Mr Farrow—Indeed. We have conducted some information sessions with some of our people, but we have actually moved more towards trying to provide some one-on-one types of training and information because of the complexities in different circumstances of our people. We do use some of the resource material available—the FaHCSIA retirement planning package and so forth. It is certainly a very useful resource. But, again, because of the different circumstances and types of disabilities with different financial situations and levels of family support and social interaction and those sorts of things, we have found that spending some time one on one with the people with a disability and also, if they choose, with their family members and carers is time far better spent at this point in time.

Senator BOYCE—Can you describe retirement for some of those people. What are they doing in retirement?

Mr Farrow—Some are spending more time shopping and going down to the local shopping centre. Some still gravitate back to work. Some of them, because we have a range of services that cover the spectrum of disability activities, still engage with some people from Bedford. But, unfortunately, and as was touched on earlier, some people tend to sit at home and become socially isolated.

Senator BOYCE—Perhaps they are going back to live with family, having not lived with family in the past.

Mr Farrow—In some situations that would be the case. In some situations, some of our people find it useful to be at the centre because they have social interaction with the various staff and people as they come and go from the centre. We are fortunate in that the centre is not only an accommodation complex. We also run a conference facility out of it. So there is quite a bit of movement of people, with people from the general community coming to and fro. There are activities like that. We also have a network of various recreational types of pursuits. People in our accommodation settings are also able to go off on camp or to the pictures or whatever else in smallish groups or larger—

Senator BOYCE—In some ways that would mimic a retirement village bus for anyone who wants to go to Chermside or the movies on the weekend. Is that what you are saying?

Mr Farrow—It can be along those lines, yes. I think it is very effective. I was particularly impressed by the comment that was made earlier about the fact that buildings alone do not make an institution or whatever the setting is. It is the policy constructs. It is the way the people interact. It is the support the organisation provides. It is the way the community embraces it. We have people from schools walking across the grounds of our complex as they are going to and from school. Those sorts of things create a little bit of a sense of community engagement.

Senator BOYCE—Can you tell us something about the age of the people who are retiring.

Mr Farrow—It really is a little bit of a mixture. Most would tend to be in the upper-fifties age group. There are some who retire a little bit earlier than that for a range of reasons. That is usually health related.

Senator BOYCE—Would more be retiring in their late fifties than are working through to 65?

Mr Farrow—Yes.

Senator BOYCE—Significantly more?

Mr Farrow—We only have a handful of people who are around that 65 age group in our ADE workforce.

Senator BOYCE—And that is just historical?

Mr Farrow—It is historical, but we see that trend. That trend is moving upwards and so that is something that we recognise we need to confront.

Senator BOYCE—You have mentioned the seeming lack of connection between FaHCSIA and health and ageing and state and federal departments. You say that there can be a disconnect between groups of people requiring support and the very nature of government programs designed to assist these people. Can you explain that a bit more for me please?

Mr Farrow—Certainly. Perhaps if I take a very broad picture to start with. One of the things that at times becomes a bit frustrating being a service provider, if I can use employment as an example, is we have people who work in our ADE workforce who want to go out and secure open employment. In a sense they have to resign or leave our ADE workforce—farewell—to move on. The program cannot be complemented

Senator BOYCE—So that they become eligible for assistance to get into open employment—is that right?

Mr Farrow—So you have that sort of ‘disconnect’. You have a problem there that presents a significant issue for the person: do they want to give up the security of having—and, look, we would take them back—

Senator BOYCE—Your average Australian would find a new job before they left their old job.

Mr Farrow—And also we have people who would like to work in two places. Some people would like to work in open employment, and we would dearly love that. We have had people who have worked in open employment in a particular setting and also worked part-time in our ADE workforce—the best of both worlds, just the same as anyone. If you want to go and push trolleys around supermarkets in the open workforce and do that, then that is fine. If you want to work a couple of days in an ADE workforce where you tend to have those social interactions that we spoke about, it is just the same as anyone else. So there are those sorts of policy disconnects.

We have some regional services and we have found on occasions it has been difficult to provide transport for some of our people, and so even though the school bus goes straight past, the person cannot hop on the school bus because that is handled by the education authorities, or whoever it may be, and unfortunately they are not funded to hop on the bus. So there are those sorts of issues; it is across the board. I think it is within the federal government in terms of FaHCSIA and DEEWR and health and aged and also states in terms of day options and accommodation and all of that. The system does not lend itself to letting people move easily. I note people have spoken about the NDIS and the opportunities for a long-term disability care and support program. There has to be a program like that, that allows people to have funding packages where they can move between and, at different times, access different types of packages. For some people it might be a combination of supported employment and open employment, a bit of a combination, a bit of recreation or advocacy or whatever else: they are in a position to be able to access those services when they need to and to choose the service providers or whoever they feel most comfortable with who will provide the right outcomes.

Senator BOYCE—I am curious: the Queensland disability act would prohibit any service provider group from supplying whole-of-life services. Is that so in South Australia?

Mr Farrow—There is a preference for there not to be whole-of-life services, but there are some services, for various reasons, that do provide that. We have people who live in our accommodation and work in our employment settings.

CHAIR—I just want to follow up on that: when you say there is a preference not to provide whole-of-life service, can you explain that please?

Mr Farrow—I think there is a feeling amongst some that if an organisation has control over the activities of someone from the time they get up in the morning—

Senator BOYCE—It is trying to stop abuse. It was part of the deinstitutionalisation.

Mr Farrow—so there would be a preference. One of the things that we have embarked upon is where there are situations where there is another provider. I will cite an example. In a regional setting, we have just built some houses for people with a disability. We are not going to provide the support because there is another quite suitably qualified and very competent service provider there. We will just contract with them to provide the support.

Senator BOYCE—And you will be the landlord, so to speak?

Mr Farrow—In effect, yes. But, unfortunately, there are some situations where there is only one landlord and one support agency.

Senator BOYCE—It has been suggested that there could be a conflict of interest between service providers providing services and providing planning services, in that they may only talk about their own services and not the range of services. What would your comment be on that area?

Mr Farrow—That is a good question. If there were appropriate forms of governance and accountability and if it were a very transparent and open process, I would not be overly worried. The issue is: how do you make sure that the process is transparent and that there are the appropriate forms of governance and accountability picked up? Obviously, you could bring into play things like various forms of audits and so forth. I would probably lean a little bit towards the government approach and say: if there were any way of differentiating, all the better, as long as there were robust systems in place and it was all above board, with no complaints and had no need to take any action. I do not know that it would be a huge problem.

Senator BOYCE—In the past, there have been situations where there were no complaints, but it has finally come out that this was because there was a culture of fear amongst parents and carers—that if they did complain they would be thrown out of the service and there were no other options.

Mr Farrow—One of the interesting things is that at times there are different regimes of penalties and potential sanctions, and they do not get invoked that often. Again, I come back to this: if there are robust and appropriate forms of governance, auditing processes, independent audits and that sort of mechanism. I also believe that in some states there are some independent authorities that do some sort of monitoring. I am not that familiar with those, but I am led to believe that there is something along those lines in either Queensland or Victoria.

Senator BOYCE—Senator Siewert raised the potential for conflict of interest between the needs of the person with a disability and the parents or carers. What is your view?

Mr Farrow—Obviously the person with a disability—

Senator BOYCE—Your organisation might often end up in the position of being a mediator, I would imagine.

Mr Farrow—Yes, on occasions. One of the issues that we confront is that and we make it clear that, in most situations—and I say most—the person with a disability is the person that we are dealing with. They have the right to either have or not have their family members or carers involved in some of those decision-making processes. Obviously there may be situations where the person’s well-being or safety might be compromised. There are some situations like that that we would have to carefully consider. But, in the main, our approach would be to look at the needs of the person with a disability.

Senator FURNER—Like Mr Heckendorf, you raised the view of having a national centre of excellence for disability. How would you see that centre operating? What would be the objectives of such a centre?

Mr Farrow—I am not familiar with Mr Heckendorf's proposal.

Senator FURNER—We did not get around to those questions.

Senator BOYCE—A centre of excellence, looking at research into disability and the like.

Senator FURNER—Perhaps I could answer it this way. We have touched on the fact that it is difficult to know where to go to find things in the system. In a couple of our submissions we made the point that we believe that there is a need for some overarching body that looks at all disability type issues and sets that sort of planning framework. In terms of some sort of centre of excellence to look at research, there is not necessarily sufficient research of the right type undertaken into some disability type issues. There have been some questions raised about the issue of unmet need. I would agree with previous comments that it is an interesting question. I think it is understated. I just make that point.

I would also suggest that with some issues to do with research sometimes some of the data is actually overstated. We have some family members looking for accommodation who will actually put their son's or daughter's name down on not just one waiting list but our organisation's list for accommodation plus the one down the road, the one across the road and the one in the next suburb.

In terms of a centre of excellence, I must admit I have not given that that much thought. I would like to take that on notice, if I may, and give it a bit more thought.

Senator FURNER—Sure. You also mentioned earlier in your introduction about the evidence that Carers Australia was providing about their website. That website is up and running. They did indicate it was a work in progress. Does your organisation use that much at all?

Mr Farrow—We do not use the Carers site that much, no. We are at the stage now where we are developing a web link for the people in our family network and we will be looking for appropriate links to other websites around the place. I would assume that we would include Carers in that as well as any other disability care organisations or bodies.

One of the interesting things with technology—and it is something that some of our family members made a point of—is that they find it a little bit confronting. In our client group we have people in their 40s and 50s, which naturally means that some of the family members and carers are in their 60s, 70s or thereabouts and have not really grown up in a technological age. They find that quite confronting. They find some of the information that comes out from various sources—whether it be government or any other organisation—is difficult for them to access. There is a presumption made at times, I think, that once it has gone out on the net it is there and everyone has access to it. It is not necessarily the case. I am a little bit concerned that at times we make that assumption—that by putting something up through technological means we are going to address the needs of anybody and everybody. I would give that word of caution.

Senator FURNER—No, it is certainly not the only opportunity.

CHAIR—Carers Australia made that point.

Senator BOYCE—It is not just about being technologically educated; it is also about having the time or knowing you should and whatever else.

Mr Farrow—That was one of the issues. Again, it may not be necessarily reflected in our submission, but one of the difficulties for some of our family members is being where to start with some of this sort of thing. A disability trust is a great idea, but, 'Gosh, what do I do to start? I am not quite sure.' It is very complicated, with all these financial tax type issues and legal considerations. The special disability trust caters for a particular group. It is a very welcome initiative, but I think there may be opportunities for that to be expanded. I do not think that some of the information is as easy to understand as it might be for some of our people—our family members. At times they are a little unsure whether or not they can pool resources. We have some family members who might not have enough to set up a trust in their own right, but there is a question of whether or not they could pool money to create that trust arrangement. Some of that is not as clear as it might be.

Senator BOYCE—Okay. That is worth knowing.

Senator FURNER—Just on information sharing, have you seen the *Planning for the future: people with disability* booklet that FaHCSIA has put out?

Mr Farrow—Yes.

Senator FURNER—Have you found that a good model to have information provided?

Mr Farrow—I think it is useful resource. One of the difficulties is that information is made available, but sometimes it is nice for it to be actually communicated in some other form. At times information comes out from government departments and there is an expectation that it is easy to read. I am not sure if that is the case. I do not know if enough attention is given to the actual needs of the audience. It may be written up in such a way that it makes it a bit confusing and people do not take up the opportunities to look into different programs for that reason.

Senator FURNER—Have you had that feedback?

Mr Farrow—We have had that feedback on a number of occasions. When the disability trust first kicked off a few years ago, we convened some small information sessions along with someone from a legal firm with whom our organisation had involvement. We spoke generally about some of that information and made some booklets and so forth available. Some people came back later and said, ‘Thank you, but we’re not quite sure where to from here, and we don’t really know if we want to go and sit down with a lawyer and start talking about those sorts of issues.’ So there has been some feedback about some of those issues. Again, it is a useful resource but sometimes we can end up with a number of like resources and there might be a need to consolidate some of those things.

Senator FURNER—One last question: throughout your submission there is an emphasis on local governments and the part they play in the system. Can you just expand on that?

Mr Farrow—Certainly. One of the potential dilemmas we face is that we leave out that third tier of government when we focus very much on the interplay between and within the Commonwealth and state jurisdictions. But if you have a look at a number of the services that people ageing with a disability may need to access, they will be services that are often generated or coordinated by or run through local government agencies. For instance, various community groups; activities; access to libraries; the tours where the local community bus goes—a lot of those things are largely driven by the local council, the local government agency or whatever. So I think there is a need to make sure that they are part of this planning framework, otherwise we will end up with the Commonwealth and the states doing what they need to do and there is no infrastructure underneath it to support. So I think it needs to be borne in mind that local government does play a very important role, not only in terms of those sorts of linkages but also as to where the parks are going to be and if there are going to be walking trails—

Senator FURNER—Access and those sorts of issues.

Mr Farrow—Access and all those sorts of things.

Senator FURNER—Thank you.

CHAIR—Can I take us back to disability trusts. You have touched on them this morning. In fact this committee, as you are probably aware, held an inquiry into them. You commented on the changes that have already been made to the disability trusts. What other changes do you think still need to be made so that they are more accessible?

Mr Farrow—There would be people far better placed than I to talk about that. The feedback we have had from some of our people—from some of our family members and other sources—has been that it is a bit hard to work out, in terms of what some of the entitlements are and how you can actually use some of the discretionary money, and what is reasonable care and accommodation. I understand there have been different changes. There is an additional $10,000 in discretionary expenditure and so forth. But there is still that uncertainty about: ‘Exactly what does that mean? What can we use the money for? How can we best use that over a long-term period to meet the needs of our people, our family members?’ So it is that sort of issue. There are, I understand, some potential recommendations that were put forward to do with taxation treatment, access to superannuation and things like that. To be honest, we are not quite sure what the state of play is on some of those things. So we are left in the dark a bit, if I can put it that way.

Senator BOYCE—I would like to go back to your point earlier that it is the people who decide whether it is a home or an institution. We are talking here about setting up plans for people with disabilities that, presumably, can be sustained after the death, or the inability to care, of the parent or carer. So we need something that is sustainable—or not just something that is sustainable but something that monitors the quality of life that is provided to that individual. How would you propose that we go about that?

Mr Farrow—In terms of the sustainability or monitoring the quality, or both?

Senator BOYCE—I mean, for it to be sustainable and good quality, I guess; for it to be sustainable quality—how’s that?

Mr Farrow—Probably the best way to answer that is to say that a robust, independent audit process would really be the only way for people to have some degree of comfort.

Senator BOYCE—Would there be any place in there for personal networks? Microboards is another suggestion that has been raised.

Mr Farrow—I think those options certainly need to be entertained. I am not as familiar as I might need to be about the actual operations of those and I have picked up on some pieces to do with a pathways project or something—

Senator BOYCE—Pave the Way.

Mr Farrow—Pave the Way project and Microboards, but I am not that familiar with the mechanisms. At the end of the day the system is really there, hopefully, to provide the range of options and choices that people want that are going to meet their needs and provide them with quality outcomes. Obviously, if the approach of self-managed funding comes into play then there will be the opportunity for people to move between services, but there are limitations.

Senator BOYCE—I imagine the vast majority of your clients would not be able to do that without someone to assist them. They could not plan it and organise it themselves.

Mr Farrow—Indeed, in which case there needs to be a robust independent advocacy type service that people could use, whether or not that is one that is sponsored or supported by the state—I use ‘the state’ for the federal or state governments. That may be an appropriate mechanism. Looking at extending some of the roles of the various guardianship and public advocate type forums may be another way of providing that safeguard. They already have, as you would know, a range of roles. That could be expanded to provide the degree of governance that you would be looking for.

Senator BOYCE—However, one of the points Mr Heckendorf made earlier was that even in group homes people can suffer from quite a lot of social isolation. I cannot imagine the public trustee spending a lot of time checking to see if someone is feeling socially isolated. Do you have any thoughts on how you would address that in the absence of parents or siblings who are worried about that quality-of-life sort of issue?

Mr Farrow—I will have to take that one on board. I will give it some thought, if I may, and come back to you on that.

Senator BOYCE—Just going back to this issue of institutions, the size of facilities et cetera, there have been suggestions, and you have made them yourself, about retirement village type facilities for older people with disabilities. Could you talk a little bit more about the options and innovations that you have seen in that area and also that retirement villages are seen as okay for people without disabilities but not for people with disabilities?

Mr Farrow—One of the reasons this was prompted is that the complex we have, as I mentioned, known as Baliana—which is a congregate setting for about 80 people—

Senator BOYCE—How many?

Mr Farrow—Eighty. We have 50 living in single independent motel type apartments and then another 30 or so around the perimeter of a property with several hectares, in the foothills, living in group homes. There are three or four people on average living in each of those.

Senator BOYCE—Everyone has their own bedroom, at the very least. Is that what you are saying?

Mr Farrow—Yes, and their own ensuite type facility and so forth. One of the reasons we having been looking at different options is the need for us to redevelop that property. It has been around for a number of decades and needs to be upgraded. At the front we have a very large oval, for want of a better word, and we are looking at ways of creating some different configurations. One of the things we have been looking at is whether or not there are opportunities to have some form of accommodation for people with a disability and their families living in close proximity so that there can be longer term family relationships and networks set up in that way.

We recognise that there is a need to perhaps reduce the number of people in the motel and have some group homes and link up with different aged-care services so that we can provide more of an ageing-in-place type of approach as people age. I should mention that we are fortunate in that because we have a conference facility we also have a commercial style kitchen, so we are in a position to help by providing meals to some of our people as well. We have started looking at a range of options there.

We have also debated how far we should go in terms of moving into community based accommodation. We currently have a number of houses being built around metropolitan and regional Adelaide. One of the things that has emerged as part of that process and through some feedback from family members is that, sometimes when some of the people leave our larger setting and move into the community, they do not necessarily interact with their neighbours and do not do some things as often as they would like, and there have been occasions when people have wanted to go back to our larger setting for those reasons and for greater security. Basically there are very few constraints on people in that setting; it does not fit the typical institutional model, if I can put it that way. People can come and go as they like; they can have friends over.

Senator BOYCE—I guess the point is: would anyone know if they were prevented from coming and going as they would like? That is the sort of question that comes up.

Mr Farrow—Yes, and really that falls largely back to the way our policies are framed and to our relationship with the state government and the way that it monitors our service. We have to maintain a particular standard of quality accreditation to continue going on, in a sense. To an extent it is largely the trust arrangement that people feel comfortable with. Family members will raise concerns with us. We have a useful network, as I mentioned, and we have various residents committees where those sorts of issues can be raised. But I take your point that there will be potential constraints on whether some of that information could ever come out.

CHAIR—I believe you took some questions on notice.

Mr Farrow—Yes, that I promised to come back to you with.

CHAIR—Thank you. That would be very much appreciated.

Proceedings suspended from 2.47 pm to 3.13 pm

WALKER, Mrs Marita, Chief Executive Officer, Perth Home Care Services Inc.

YOUNG, Mrs Melissa, Manager, Systems and Business Development, Perth Home Care Services Inc.

Evidence was taken via videoconference—

CHAIR—Welcome. I would like to thank you for appearing via videoconference from Perth. I understand that you have been given information on parliamentary privilege and the protection of witnesses and evidence. Is that correct?

Mrs Young—That is correct.

CHAIR—We have your submission which we have numbered 47. I invite you to make an opening statement and then we will ask you some questions.

Mrs Young—Thank you. Whether we are young or old or a person who needs support or a carer we all have one thing in common: our hopes and dreams for the future. How we plan for that future depends greatly on our experience, knowledge and ability to get good information to help us on our way. Perth Home Care Services is a community benefit organisation that has been providing support to the Western Australian community for 40 years. Our vision is: people living at home with dignity. We assist people in the community to be in control of their lives, connected with family and community regardless of circumstances, by recognizing each person’s uniqueness and working with them to develop the support they need. With an annual turnover of $36 million and 850 staff supporting 1,200 people per fortnight, including over 300 people with individualised disability support, we are a recognised leader in innovative approaches and individualised solutions.

Our submission draws on our experience with older carers through our time off and planning programs. Often we find that the best way to explore issues is to ask good questions. We ask ourselves, ‘What would it take?’ and we encourage people to think about what it would take to live a good life. So what would it take in the context of the committee’s terms of reference? What would it take to help people with a disability and their carers to plan for the future? We should: (1) develop pathways to access planning support through many sources, such as GPs, therapists, local area coordination, hospitals, community groups, Carers Australia, CRCs and adequately fund program development and organisational implementation; and (2) provide easy access to planning opportunities for people to have good conversations about what is important for them and what their concerns are for the future. What would it take to ensure continued quality of life for people with disability as they and their carers age? We should: (1) make funding between disability and aged care programs seamless for the person needing support; (2) listen to the voices of people ageing with a disability and their carers to see what type of support will make the most difference and measure the outcomes of that support rather than the hours of output measured in current models; and (3) allow funding to provide for truly flexible responses to the needs of people. This means using a model of funding along a consumer directed continuum, not a one-size-fits-all approach to ageing, disability or carer issues.

In addition to the practical types of support needed, such as home help, cooking and transportation, other types of support that will make a difference to people’s quality of life include affordable and appropriate housing, opportunities for community connection and reciprocity, and planning for future needs. What would it take to eliminate inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers? We should: (1) reform funding mechanisms for both the aged care and disability sectors; (2) include consumer directed funding models, including respite, which allow a real choice for the consumer; and (3) encourage family leadership in the development of models and recognise their power in making decisions for themselves. What would it take to help carers to find an appropriate answer to the question, ‘What happens when I or we can no longer afford to care?’ We should: (1) approach the question of planning for the future as early and as regularly as possible; (2) recognise that the lives of people ageing with a disability and their carers are forever intertwined; (3) be available to have the conversation; (4) provide planning material in accessible formats using simple and plain language. This would include a website as well as print media; and (5) provide and promote social media opportunities driven by family leadership and auspiced by an organisation to discuss issues around disability, ageing and planning the future.

So why is this important and why are we here today? It is because this is not a disability issue, an ageing issue or a carers issue. This is a personal and community issue for us all. This is an opportunity to ask, ‘What would it take?’ and have the courage to listen to the answer. Thank you.

CHAIR—Thank you. Mrs Walker, do you want to add anything else?

Mrs Walker—Yes, I might add that our practical experience has come over a number of years now in which we have been involved with families. We have had opportunities to provide them with what we have been talking about—being flexible, being able to plan with them—and we have some examples about how we do that: either as individual families or with groups of families together. There is an approach called a Big Plan or there is person-centred planning. We are making this submission from having some experience that you can do it and that it does work, so our comments are coming from some practical experience.

Senator BOYCE—I note that you are the first organisation we have spoken to so far that actually provides planning services, so perhaps you could tell us a bit more about the Big Plan.

Mrs Walker—The Big Plan is an approach where six families and the people they support come together. There is an introductory session where a description is given about what will happen. The Big Plan then occurs on five different sessions that run for three hours over the next five or six weeks. There are a range of activities that are worked through with facilitators, which help people think about who their family is, what their supports are, what their dreams are and what the things are that can help them get started to actually make those dreams become a reality. That is the format of the Big Plan.

Senator BOYCE—Would the Big Plan actually involve developing a plan, or is it thinking about the tools you need to then develop a plan?

Mrs Walker—It starts you on the first steps.

Senator BOYCE—How many people have done that program to date?

Mrs Walker—We have had some funding through FaHCSIA. It is small numbers, at this stage—about 20-25.

Senator BOYCE—That is, 20-25 families—is that right?

Mrs Walker—Yes.

Senator BOYCE—Have you done any evaluation or do you have any anecdotal information about what those families have gone on to do, having done your program?

Mrs Walker—Yes. Just to give you a timescale, it has been over the last year that we have had three groups of five or six. The second group of people, who are from our mental health program, are just at the start. We have also had people get together again, and we are in the process of planning the second reunion of the first three groups. So we are following up people and have evidence of what has happened for them. It has been very positive. We also have a more formal evaluation occurring for what will be three groups of people from the mental health area.

Senator BOYCE—And the evaluation will happen when?

Mrs Walker—It has started, and it will be completed by June next year.

Senator BOYCE—Could you tell us what some of those anecdotal results have been of the people attending the Big Plan. I am thinking it is probably too early to say, yes, they have all developed plans that are lovely and flexible and sustainable and will work until at least 2080.

Mrs Walker—The most recent description I have heard was from one of the people in the mental health group. There were two people who spoke about their experience. One was a parent who had four children, and he experienced mental illness himself. He described very clearly how it had helped him focus on what it was that he could do. When he looked at some community mapping that had been done as part of the Big Plan, there were a number of things he was following up about how he could be much more contributing and positive.

I will try to come back to a more specific disability example, given this Senate inquiry. Jason is a young man who has experienced quadriplegia and who we are supporting. He was part of the Big Plan. One of the things that was most important for them was to be able to go on a camping holiday. Through the Big Plan they looked at what the things were that would enable that to happen, and I can be very clear that they have come back—that trip has happened. The sorts of difficulties that they thought might make it all too hard for them were that they were able to take Jason and they were in camping grounds and his care was able to be managed. One of the things they had a dream about was to have that holiday and it has happened.

Senator BOYCE—Thank you. I take it from what you are saying that you would run some sessions for people with disabilities and their families, and others for people with mental health problems and their families. Is that correct?

Mrs Walker—That is right.

Mrs Young—Yes.

Senator BOYCE—There has been evidence about the difficulty of planning that people who have a family member with a mental health problem often have because the episodic nature of the disability can often cause people to feel almost treacherous by planning because it assumes that the person cannot get better. Can you talk a little bit about some of the issues that are relevant to the barriers for planning, both for family members with a mental health problem and the general barriers to planning for people with disabilities?

Mrs Walker—The general barrier is mostly about people being able to feel that it is something they can even start to think about. This is one of the things we learnt most about in our contract with our time-off and planning program. For many people, just coping day to day and week to week is really all they can manage. So the time-off and planning went together because if you could give people time off, then they were able to move their headspace into thinking about planning. But not everybody could do that. People are very much on a spectrum, as everybody else is in the community. There are people in the general community who do not have the barriers of disability who do not plan their lives and there are other people who do that in a very considered and ongoing way.

But the specific difficulty for people with a disability, the opportunity to be able to take a breath, was very important, as was alongside of that for us to have the opportunity to say as an agency, ‘Now, we’ve been able to provide you with some time off, and we’d like to encourage you to think about the people you have around you to help you think about the future.’ It might not be that particular time off; it might be the next one that occurs for them. The combination of the opportunity to take a breath and the encouragement to think about planning is important, and to then be able to take that along what is not a short and easy process—it can be long and difficult—and support them along the way.

I will just say a bit more about the mental illness part of the question.

Senator BOYCE—Yes, please.

Mrs Walker—We have a very strong focus in our mental health services on the concept of recovery. Recovery underlines the contemporary thinking about mental health services. People may have a full recovery from their episodic illness or they may experience the opportunity to recover even though they might have ongoing illness and symptoms that need to be managed. But they are still able to recover and live their life within the constraints of whatever their episodic or ongoing mental illness might be.

Senator BOYCE—Would that change the nature of planning for both the individual and the family concerned about their long-term welfare?

Mrs Walker—Not in fundamental ways. It is really about people having a home, a job and friends, and that is fundamental for whatever the situation is that you are planning for.

Senator BOYCE—Have you found that the majority of people with mental health problems of some sort that you have offered big plan to are happy to plan with their families?

Mrs Walker—We have invited people to participate. It is not for everyone. That is one of the key points for us to make. We have other ways that we encourage people to do planning. Some people would prefer to do it on an individual basis. We have other tools that we can offer people. For some people, it is just a conversation that they have in an ongoing way. I would not want to make a sweeping statement that all people with mental illness would want to participate in a big plan.

Senator BOYCE—No, I am asking if there are different ways of approaching the planning process for people with a mental health problem who generally would not have an intellectual disability and their families compared to people with intellectual or learning disabilities.

Mrs Walker—The difference between families and people is greater than the difference between mental illness and disability. There is a wide diversity of families and situations, and that is probably where the greatest differences are.

Senator BOYCE—But you still see the point of a disability or a mental health problem as the major distinction between the two groups that you offer the big plan to—is that correct?

Mrs Walker—Not necessarily.

Senator BOYCE—Sorry, that is what I thought you said.

Mrs Walker—No, I said that we have offered them differently, but it has been more about circumstance rather than making a deliberate decision that we would only offer them differently.

Senator BOYCE—Okay. Do you have waiting lists for people to attend the big plan sessions—not necessarily formal waiting lists?

Mrs Walker—It is early days. No. Not many people know about it as an option. We have invited people as we have had the capacity to run programs.

Senator BOYCE—I presume you have not advertised it because you did not want to raise expectations you could not fulfil—is that correct?

Mrs Walker—That is right.

Senator BOYCE—Do you think there would be a large number who would be interested in doing it if the courses were more generally available?

Mrs Walker—I think so, yes. We have very enthusiastic advocates. We wanted to know it was going to be something worthwhile. We now have a number of people who are very willing to talk to others about what a positive experience it has been for them. I anticipate that were it more widely available it would be popular.

Senator BOYCE—You talked a bit earlier about other planning options. Could you tell us—either now or you could take it on notice—about the different planning options available from Perth Home Care Services?

Mrs Walker—Many of our families that we support come to us through individualised funding packages that they have received. For them, we are looking at planning that is about how they want to utilise the funding that they have been given. That might happen with direct contact between different members of their family and supporters and members of our staff. We have another approach, called person centred planning. There are a couple of tools within that, called MAPS and PATH. There are other possibilities. Earlier I mentioned time off and planning. People might come to the agency for some specific respite, which is the time off, and we will use that opportunity to talk to them about their plans for the future.

Senator BOYCE—You also mentioned PIN, which I do know a little about, and another group, called Vela Microboards Australia. Can you tell us more about those, please.

Mrs Walker—Vela Microboards Australia is a small association that is sponsored by Perth Home Care Services. It is modelled on Vela Microboards British Columbia. A microboard is a formal organisation set up specifically to support one individual. Microboards has been operating in British Columbia for 16 years now, and there are over 1,600 microboards now set up in British Columbia. Some years ago now Linda Perry, who is involved in that organisation in Canada, was brought to WA. A number of families got together and heard about it all and felt that they would like to promote the availability of that concept here in WA. Vela Microboards is now in its third year since it was established, and it has a number of pioneer families. We now have two, almost three, microboards that have been formally constituted. We are anticipating that there will be more over the next few years.

Senator BOYCE—When you say ‘two, almost three’, do you mean the third one is nearly formally organised?

Mrs Walker—Yes. That is right.

Senator BOYCE—How many individuals will those three microboards support?

Mrs Walker—The microboard is always for one individual.

Senator BOYCE—That is partly what I was asking. Is there any connection between the three individuals that have them?

Mrs Walker—No. The families involved in Vela Microboards have been what we call pioneer families. They consider themselves a learning community. They have found that the majority of what they are doing—well before they get to the point of formally applying to have a constitution and so on—is building networks. The families have learnt a lot from working with each other and from each other. So the families have come to know each other, but the individuals do not have particular connections.

Senator BOYCE—So you are auspicing Vela Microboards Australia. Is that right?

Mrs Walker—That is right. They have made the decision not to become incorporated separately themselves, but each microboard is incorporated.

Senator BOYCE—And PIN?

Mrs Walker—PIN is Planned Individual Networks.

Senator BOYCE—Do you auspice that as well?

Mrs Walker—We are in some discussion with them. They are separately incorporated and have been for six years. We are in some discussion as to whether they will come to have a closer relationship with us as a supporting organisation.

Senator BOYCE—You have said in your submission that sometimes there is a cultural expectation that people will provide the caring role to their son or daughter with a disability lifelong. This is not an expectation we have of the general Australian community. What should we be doing to change that expectation and whose expectation do you perceive it to be?

Mrs Young—I think ‘cultural’ means a couple of different things. There are people from other cultures, for example, for whom it would be normal state of play to care for people in their homes or to care for immediate family all their lives. There is that aspect of it, I suppose—

Senator BOYCE—Which is fine, if that is what people want to do.

Mrs Young—That is right. The other cultural part of it is: if you have a child with a disability, the expectation is that you will care for them lifelong. So I am not sure—I am just trying to think of how you might change that. I suppose that families will always want to care for their members, regardless of whether or not those members have a disability, but, fundamentally, there are a lot more choices for families where no family members have a disability—there are a lot of things that you can do. On the other hand, if you have a family member with disability, you might feel your options are limited or there might be funding issues that limit your ability to plan for all the things that you would normally expect to happen in a family—where the child grows up, leaves home, gets a job and all the normal stuff that you would imagine. Sometimes that is difficult and it really speaks to the heart of the planning part of this—that people need support to have planning, to make those things happen. Just because there is a family member with disability does not take away from wanting, for your child, that natural life progression of things.

Senator BOYCE—In your view, would that be the choice of the majority of people with disabilities and their families if the supporting services were available—to follow what is considered the average life path of Australians?

Mrs Walker—I am sure it is. It would be the choice if it were provided in a way that they could see it was a positive experience for their family member.

Senator BOYCE—And sustainable, presumably?

Mrs Young—Yes, and sustainable. It has been our experience—and it is interesting—that sometimes the adult child with disability is really keen to take off in a particular direction, but it is their ageing parents who have a hard time imagining what it would be like for that child to be out in the world. So there are some considerations that you need to look at. Everybody is different and it is important to say that. Not everybody wants to do the big plan. Not everybody does a group thing. Some people do it individually and, just like you and I, sometimes a parent is ready to let go and sometimes not.

Senator BOYCE—A number of submitters have mentioned that it seems to them somewhat ironic that Australians without disabilities can move into retirement villages or those sorts of settings, yet older people with disabilities, because of government policy around congregate care et cetera, cannot do the same thing. Would you like to comment on that and what you would perceive as some of the better lifestyle setting options for elderly people with disabilities?

Mrs Walker—This comes to our point about housing being an integral issue in all of this. If people are older with disability then they really have much the same options as older people have in the general community. If you have some individual funding, for example, you can have that funding support you in a retirement village, but it might just be a retirement village that is for everybody. The issues around housing and retirement are very similar for people with disability as they are for people who are ageing in that we have very few options. If you have individualised funding then you can put housing and support together in more creative ways than is possible if you think of housing for disability and housing for aged care being separate.

My point is about housing having more options than we have now. In aged care you have residential facilities, high care and low care, and retirement villages—that is it. In disability there are still congregate options. I would still call group homes congregate options. There is a growing excitement about the possibilities for other sorts of combinations of care and support. Our organisation currently has some funding for piloting what we call 'home share' both within an aged-care stream and within a disability stream. That is where people share their home and have a reciprocal relationship and some level of support provided. You have a householder and a home sharer. We also have situations where we are looking at co-residency, where the person with disability is a co-resident with someone who is living in the home but also providing a higher level of support on a salaried basis.

In terms of generally and at the retirement age there is a whole lot more possibility that can be creatively developed if you have people who have individualised funding and you can really look at what it is that they want for themselves and what a good life would look like for them. Going back to the substance of all this, that is if you have good planning.

Senator FURNER—Can I just ask some questions firstly around the TOP initiative. When a carer moves into respite for some time, where do you source the replacement carer for the particular client? Is it someone the client has had experience with before or is it a case of a renewable carer coming in while the person is on respite?

Mrs Walker—It can be all of the above. The thing about TOP is that we do not provide respite just by having someone come in and stay with the person with disability. It might be that the person with a disability goes on holiday. There might be a range of different ways that that is done, but the TOP funding might supplement or pay for that. It might be that there is a family member who can come in and care for the person but what enables the primary carer to have some respite is that they—the carer—have a holiday. Our funding can supplement that up to $500. It is just a small contribution but it has often been what has made the difference to enable them to go and visit a relative who they have not seen for a long time. It may be that there is a course that the person who requires support is going to attend, and the funding may enable that to happen. That provides a respite effect. So it is looking at the respite effect that is achieved in a very wide range of flexible ways. It is not dependent on finding a support worker. That is the traditional way. We do a lot of that sort of work within our HACC funded program and individualised funding that is for family support. We have hundreds of support workers on our staff, so we do that too. But what has been more interesting about the TOP program is the great effect you can achieve by being more creative with the respite funding.

Senator FURNER—Have you identified any substantive issues associated with the use of the TOP initiative, maybe with someone coming in new or with the disabled client having some time off?

Mrs Walker—If you do not plan it well. We have some experience with some other funding that we have had, where other agencies have been involved in doing the upfront stuff and some of it has been done just on the phone and just with the carer. If you do not take the time at the beginning to establish a relationship, work out what it is that people really want and will benefit from and do a good match with the person who is going to have the relationship, that can mean that it does not work. I will just give you a very quick example that occurred when we were asked as an agency to provide someone who could provide some respite by assisting someone to go and attend some appointments. When our support worker arrived, the person was not willing to go. To us, that was not a major surprise because we had just been asked to provide a body and we were not involved, and the person that we were being asked to take out had not been involved either. It had been set up between someone on the phone and the primary carer. It was not really a surprise that that did not work. It is about having good planning and establishing credibility and trust between us as the agency looking to assist and the people that we are assisting.

Senator FURNER—What sorts of training programs do you provide your carers with in that regard?

Mrs Walker—We use the term 'support workers' for the people that we employ. When we are recruiting, we really look very much at people's values—do they have a sense of the people that they will be working with as people first; will they be able to establish a relationship with them and be able to communicate and think about what it is that they are doing and how they are doing it and work in partnership? Those are the sorts of things that we look for at the stage of recruiting. If people have some of the more established competencies—a certificate II or a certificate III—then that might be beneficial, but it is not essential. Then often we will provide some specific training that relates particularly to the person that they are going to be supporting—working with someone else, having the opportunity to meet them and their family. There is a range of what we call specific buddying and support that is related to the person they are supporting.

Mrs Young—Overall, however, in the last couple of years we have had a concentrated effort on the person centred approach. For the last two years, we have had annual training with all of our staff—not just our support workers but also office based staff from all areas of the business—to look at how we might use a person centred approach, looking at whether a person has a disability or they are ageing or they have a mental health issue. The person is at the centre of the support that is being provided and it is not about what is convenient for the organisation; it is very much about the strengths of the person, looking at those strengths and how we can build on those strengths when we are supporting somebody. We look at how people can make choices and decisions for themselves and be present and participate in the community, for example. We look at people's valued roles and contributions in the community. So we look at the support with a person centred approach. That is how we work. We have done a fair bit of work around getting staff trained up in that area.

Senator FURNER—Thank you.

CHAIR—Thank you. Could I pick up on where we have just left off on training and go a bit broader. I am wondering if you can comment on training more broadly in the sector and the development of support workers—particularly in WA, because we know that there is a labour shortage and those issues that we hear a lot about in the care sector. What is the health of the sector in terms of training people coming into the sector and making sure we are supporting and building the workforce?

Mrs Walker—We have had some opportunity to do that over the last few years and we have developed as an organisation a program called Partners in Change, which was specifically targeted towards people who might not have thought that they were ready to sign up to a certificate II or certificate III but who were interested in working in the disability or mental health sector. We took that initiative as part of some respite capacity building with some funding from FaHCSIA.

The Partners in Change course has been available to people who were not working in the sector to generate confidence and do a very concentrated focus on what it meant to be working in a person centred way. That course ran over a period of seven days over a few weeks and was very positive. We are now in discussion with the Disability Services Commission in Western Australia and also some initial discussions with the Mental Health Commission, which is newly established here in WA, about there being more opportunities for that Partners in Change course or slightly shorter versions of it to be available.

That is not a substitute for what is happening in the sector in terms of the certificate II or certificate III courses, but we feel it is actually more targeted and more focused on working in partnership with people and will provide things that families will value more.

CHAIR—Thank you. You were talking earlier about offering the Partners in Change course to people outside your organisation.

Mrs Walker—We were offering it to people who were not already working in the sector. That was through that period when we were absolutely desperate.

CHAIR—Okay. Thank you. You said that you had been talking to the Disability Services Commission and the new Mental Health Commission. Has that been hopeful in terms of ongoing funding for the process?

Mrs Walker—Yes, it is hopeful. It is still a huge task for the sector as a whole. In our own organisation we have 700 or so support workers and direct care staff of other sorts. We are planning to do that as an internal exercise over the next two or three years with a two-day version of Partners in Change. There are many other organisations with very large numbers. Yes, the discussions are positive and hopeful. There are a lot of people in a lot of organisations and new people who will be coming in over the next two, three or four years. We also need to be doing other things. Partners in Change is not the only solution. There needs to be other things that are basically about cultural change within organisations, considering that our role as formal service providers is to be working with people and not doing to them.

CHAIR—I will make this my last question, because I realise we have gone over time because of technical difficulties. You said there needs to be more. Do I take it from that that it is not available as yet and that more needs to be done to provide it in terms of funding and developing the programs? I am trying not to put words in your mouth, but I am trying to look at what the current state of play is and what we should be saying into the future.

Mrs Walker—There is a combination of doing what is being done currently somewhat differently, which is about cultural change, and there is still need for more acknowledgement of the value of planning and that that actually does cost time but that how you do it is critical.

CHAIR—Thank you very much. Your last point was particularly important for this committee, so thank you. All your points were, but that one says a lot, I think. Thank you very much. I do not think you had any homework, did you? We have given most of our other witnesses homework! Thank you very much. Your time is much appreciated, and I apologise for keeping you waiting at the beginning.

Mrs Walker—That is all right; thank you. If in your further discussions you need more information about what we have said, we are happy to have homework.

CHAIR—Okay. We may give you some written questions on notice. Thank you.

[4.05 pm]

DAINTON, Miss Amelia, Private capacity

DAINTON, Mr Ben, Private capacity

DAINTON, Mr Bruce James, Private capacity

DAINTON, Mr Edgar John (John), Private capacity

DAINTON, Mr Mark, Private capacity

DAINTON, Mrs Rae, Private capacity

Evidence was taken via videoconference—

CHAIR—Good afternoon. I have to do some official stuff before we get started. I would like to welcome the Dainton family—there are more than we expected, which is absolutely fine, and I will get you to say your names in a minute—who are appearing via videoconference from Perth. I understand you have been given information on parliamentary privilege and the protection of witnesses?

Mr J Dainton—Yes.

Mrs Dainton—We have.

CHAIR—Do you have anything to say about the capacity in which you appear today?

Mr J Dainton—I am a parent and carer of our youngest son, Benjamin. My wife also is a parent-carer, so I will let her speak next.

Mrs Dainton—I am the mother of Ben. We are partners in caring.

Mr J Dainton—We are individual witnesses.

Mr Bruce Dainton—I am also appearing as an individual witness.

CHAIR—Who else do we have?

Mr J Dainton—We have Benjamin, who is the person we care for—about 12,000 hours a year—and at the last minute we have brought our granddaughter, Amelia, and our eldest son, Mark.

CHAIR—Hello. You are very welcome. I would like to thank you very much for your submission. We have it. It is submission No. 66. I would like to invite you to make an opening statement, and then we will ask you some questions. We have the additional documentation you provided as well, thank you.

Mr J Dainton—Thank you very much. First of all, I would like to thank you for inviting us to provide the committee with the information to help meet the purpose of this inquiry. Our son Ben has Down syndrome. He is hearing and speech impaired and cannot read or write. Ben is physically strong but lacks the normal skills, particularly fine motor skills. Ben’s present lifestyle circumstance is that he is fully dependent on us for his protection, accommodation, daily living, medical care and transport. He also has intellectual limitations. Ben has the extra disadvantage of having to live with the lifestyle of aged parents, which would be near impossible for any 26-year-old man. Ben needs to be out in the community and likes to socialise, but at times he is unable to conduct himself in a socially acceptable manner. People around Ben need to be tolerant and accepting of him. He can sense if he is not accepted, and this occasionally shows in antisocial behaviour. We love him. We enjoy his company. Caring for Ben is our lifestyle.

We estimate that Ben receives about 12,000 person hours of service from us each year, and there are only 8,760 hours in a year. We have been unable to find any agency or service that can continue to provide for Ben in the way that we are doing. Ben receives funded respite care. While Ben is in respite care, our duties of caring for his needs continue in the form of business administration needs. The demands of the agencies significantly increase the stress in providing care.

As we age, we are finding the task increasingly difficult to provide Ben with the lifestyle of community living he needs. We are very concerned for his future. There is nothing available in the broad range of the disability sector that can fit Ben’s present and future needs. His future is bleak indeed. We have therefore created a provider agency business which Ben owns and which stays with him for the duration of his life. It is called Ben’s Administration Company and we believe this solves most aspects of the problems of providing for Ben when we can no longer perform the task. We do not have the personal resources to carry out this plan.

Its success is dependent on directly accessing the disability funds allocated in the parliamentary budgets of state and Commonwealth jurisdictions.

At a meeting in July this year, the Disability Services Commission told us this plan had to be discarded for the purpose of establishing a contract. We looked at the trustee model of the Commonwealth, but it has many disadvantages and is far too complicated. We would be very reluctant to try to use it because it does not allow the cared for person any proprietorship of their own assets and income. We have the experience and the evidence that the BAC model is a very efficient, low-cost delivery system of disability funds. It clearly works in Ben's best interests.

In order to make the changeover for Ben from being in our full-time care to care outside the family home, we have made application for funding to facilitate the gradual changeover on the combined application process form—the CAP form—for the Intensive Family Support grant, or the IFS grant. This process has been repeated many times over several years for us by an agency, but has always been rejected. The two original conditions set by the Disability Services Commission for Ben's Administration Company to operate was that it had to be legal and it is to serve only one person, and we are doing just that. The Disability Services Commission seems intent on preventing BAC to draw on Ben's grant unless we complete the continuously changing complex form and demands for information already supplied in the business plan and in the CAP form. The DSC is asking us to address undefined issues with the draft contract without explaining what those issues are. The stresses caused by the current approach are justified by the phrase 'working in Ben's best interests', and we find this intimidating.

The Disability Services Commission presented a draft contract to BAC, which we signed in July—the same week that the federal minister approved the BAC model! That draft contract is complicated, unsuitable for a sole trader operation. The draft contract is meant for a different organisational structure. During the past 20 months we have spent more than 3,000 hours complying with the DSC requests. The financial costs were at least $15,000 over that period. The DSC is, in effect, threatening to stop the funds flowing to BAC if we do not comply with their changing rules and this compromises the plan and the objectives of BAC. Should the DSC continue to refuse funding to BAC from Ben's grant, we will apply for funding from the Commonwealth's Respite and Carelink Centre. Our fallback position is that we will care for Ben until we drop. What other options do we have in this punitive environment when we are genuinely trying to be transparent and accountable? We are now in a type of bureaucratic vacuum. The BAC is not a reinvention of the legal wheel, just a different way of getting the same wheel to carry the same load.

CHAIR—Thank you. Does anybody else wish to make an opening statement for comment before we go questions?

Mr M Dainton—Yes. As the eldest son, certainly my consideration is that in the event that mum and dad are unable to care for Ben, I would feel responsible, along with my brothers and sister.

CHAIR—Does anybody else wish to make a comment?

Mrs Dainton—No, thank you.

Senator BOYCE—I should point out to the Daintons that I have a daughter with Down syndrome who is 26. I was interested when you told me that Ben was 26. So I am very interested in what you are doing. Are you aware of others in Western Australia who are attempting to set up the sort of structure for Ben's future that you are?

Mr J Dainton—The answer to that is yes. Since we got this off the ground we have had many friends come to our home asking us how to do this. We know of some people who either cannot or will not accept any services from the Disability Services Commission because of the complications and the rules that they have—it is just not worth the effort. One of our friends has said, 'If this goes through I will accept funds.'

Senator BOYCE—The Disability Services Commission funds presumably are going to service providers to be provided to people with disabilities—or are they coming direct to families?

Mrs Dainton—Not yet, unless they have done or are attempting to do what we have attempted to do. In the specific case John was speaking of, the mother has chosen not to apply because of the extreme difficulty and the rules and regulations. Her son is extremely disabled with very high needs, and she and her husband share the load. But she said that if anything happens with this one and it comes to fruition she would be very interested in pursuing it herself. There are a few others who are also watching what we are doing and hoping that they can perhaps do it themselves too.

Senator BOYCE—I am aware of two families in Queensland that have set themselves up as companies to receive and distribute funding to their own child, not so much as part of succession planning but just to have the control over it. Obviously you have done a lot of work in planning for the future and working out what you want to do. You presumably had discussions with DFC along the way. What were they telling you about this structure whilst you were getting organised?

Mr J Dainton—When we got the approval for the grant, the Disability Services Commission did not say how much it was; they just said the application was approved—but subject to something like seven groups of legal documents, and they did not include those with the approval. I set about trying to find out what the conditions were under which we would have to accept the grant, and it took many hours of work to try and extract from the Disability Services Commission what all the rules were. That is where a lot of the cost went. They were refusing at first to even look at our model, but the director in charge became interested and involved the rest of his staff. We had to produce a business plan, which they did not accept—they wanted a part of it expanded—and they gave us a long assignment to produce another business plan. It was just so long and expensive that we have reached a point where we would prefer to deal directly with the Commonwealth rather than the state. We find the state very difficult people to deal with.

CHAIR—Is the business plan you sent us of February this year the subsequent one you were asked to prepare?

Mr J Dainton—Yes, that is the second one we were asked to prepare. They had a problem with continuity of service for Ben. That was only one of the problems which we addressed in the business plan that you have.

Senator BOYCE—Is the letter from the Disability Services Commission to you and Mrs Dainton headed ‘Ben’s administration company’ dated 16 April this year your most recent correspondence with the department around the company?

Mr J Dainton—No. We got a letter in July that indicated that the budget of $93,000 they had previously agreed to had been reduced to about $71,000. There were additional conditions put on us to proceed with this.

Senator BOYCE—This letter written to ‘Dear John and Rae’ in April said that the general terms of the offer would include a pilot program and that there would be an ex officio staff member, and it sets out how the money would be split up and talks about the two-year formal trial. It ends by saying, ‘To accept this offer, please write to me with a formal letter of acceptance.’ One would think, reading this letter, that this was part of a contractual arrangement that was going to be signed, sealed and delivered.

Mr J Dainton—Rae and I presumed that that was in fact an offer as such and we did write a letter of acceptance as requested, and in that letter of acceptance we included some of the conditions we wanted in that contract which we considered were in Ben’s best interest. They later on seemed to indicate they did not want to accept our conditions and in doing so they rejected the business plan they had already asked us to produce.

Senator BOYCE—Do you think you are just dealing with bureaucratic stubbornness or is there a deliberate attempt to foil this effort to develop some independence?

Mr J Dainton—The answer to both questions is yes. They are doing both very successfully.

Senator BOYCE—I guess it is somewhat disappointing to hear that you are not being allowed to proceed with what would appear to be a very well-thought-through way of trying to have some sustainability around it. Could you talk a little bit more about how Ben’s administration company will work now and into the future, if and when you get a tick on it.

Mr J Dainton—To answer your first question, it is working well now. We had to start it in May, before 1 July, because the funds cut out and we had to use our own funds and Ben’s funds to pay carers. The second part of it is that when we got back from holidays in September, thinking there was going to be money in Ben’s bank account, there was none and we had to transfer $25,000 of our own money into Ben’s bank account to be able to pay carers. Subsequent to that we wrote an invoice asking them to pay for the first three months of care given to Ben by his business. That invoice was for approximately $22,000 plus GST. It works out as $24,000 for the first three months of care given to Ben. We were able to supply a service to Ben at something like $14 an hour cheaper than any other agency, which means that on the budget of $71,000 they have given us—which is a much reduced budget on which we cannot supply the service to Ben that we were originally told we could—we can still get nearly a thousand hours of service out of the $71,000 that we would not otherwise get.

On the question of continuity, there are people named in that business plan who have agreed to, if we were suddenly taken out of the picture, step in and be his administrators—apply to the courts for administration on a short-term temporary basis—until the family sorts itself out. That is assuming we were both taken out together. Alternatively, if we gradually fade out, as people do, we hope that over the next 10 years—in fact, we have this in place—when we will be in our 80s we will gradually transfer the administration order from the administration court to someone else who the court will accept. We hope to be still alive to watch this thing transfer and continue.

Senator BOYCE—I am not asking you to name names, but when you say ‘over to someone else’ can you tell me who you have in mind there—family members, outsiders, a combination or what?

Mr J Dainton—We would hope it would be a family member but most of our family have children of their own and they have time problems and responsibilities. We think that the main carer we have may take it on. Ben requires an administrator. That is clear. He is legally incompetent so we will always have to have an administrator. The weakness in the plan is that the Disability Services Commission will put in someone to be his administrator and that will be a near disaster. We are hoping that with our broad range of friends and our family’s friends that there will be someone come in to be his administrator. We have a granddaughter who has been married for two years who is a possibility. I would not even approach her now. But, as years roll on, people come into your family circle and we have great hope that, either through the church or through our circle of friends, there will be continuity for Ben.

Senator BOYCE—Just for the sake of completeness—and I think I know the answer to this question—what prompted you to go about setting up Ben’s Administration Company?

Mr J Dainton—The short answer to that is that we discovered there was a vast difference between the grant that he was given and what was made available to him. There were many rules and conditions that were being dictated to us as to how we were to use this grant and it cut right across our family lifestyle. We had to do something about it.

Senator BOYCE—Could you give us an example of some of the rules and conditions that you considered were unacceptable?

Mr J Dainton—I would like my wife to pick up on that one.

Mrs Dainton—It is hard for me to remember the exact details, but when the Family Support Association—and that is the agency with whom we dealt—was formed, there was one lady half a day five days a week and you approached her and received help. If she was not able to help, she was able to go back to her LAC and request some more help.

Senator BOYCE—The ‘LAC’ the local area coordinator; is that right?

Mrs Dainton—That is correct. That was during the days when Ben was at school so it was fairly simple. Then they moved and they had another person administering it as well. We were receiving reasonable help when we required it, but they now have become a very large establishment. They have gone from two to nine people, with cars and uniforms. They are still dictating to us that we cannot train our own trainers and that we are limited to three months budget, so there is no flexibility and we have incurred a lot of difficulties in handling them.

Senator BOYCE—By being limited to three months budget, you mean you must expend the money within 12 weeks or lose it—that sort of thing?

Mrs Dainton—Or lose it, yes. We are not the only family that that occurs in. You cannot ever plan ahead. You need to know that, if you need it less in three months, it is there for you if you need more in the next three months. They have become very dictatorial. Living in a small country town they have been friends so it makes it even more difficult. One time when we had to apply for extra funding, the agency that we applied to said, ‘Have you ever thought of managing your funds yourself?’ It really grew from that.

Senator BOYCE—Have they done that with other families? Are you aware of whether they have assisted other families to manage their own funds?

Mrs Dainton—That particular agency was a Perth based one that we had to go out of the circle to apply to. We thought it was called a top-up fund. We have since been told that that is not a polite way of explaining it, but that is what it was at the time. There are other families who have approached the agency that we were dealing with in Albany and have said that they will not accept funds unless they can manage them themselves. But they are fairly new at it, their child is still at school and they are younger parents, so they are not in the same situation.

Senator BOYCE—Going back to the Perth agency that you mentioned that suggested looking after the funds yourselves, are you able to give us the name of that agency either now or confidentially later?

Mr J Dainton—It is the Commonwealth Respite and Carelink Centre. I refer to them in the submission. We spoke to the lady in charge there when we went to ask whether they would deal with us directly. We had already registered Ben’s administration at that stage. She thought that that would be okay and that it was a very good way. But, later on, she just denied even remembering anything about it and, later on again, when we applied for funds—and I have mentioned this in the submission—they refused to deal with us.

Senator BOYCE—Yes, I remember that point. You had some somewhat scathing comments to make about the disability industry. I must admit that I have always been somewhat puzzled that the way governments account for funding that goes to service providers is to ask the service providers what they do with it. There is very rarely any sort of auditing of families or of people who receive the actual services. Would you tell us a bit about how you think that should work in order to overcome what you describe as the industry wastage, I guess, of funds.

Mr J Dainton—Yes. I have a lot of ideas about that, as you would realise. We have another son, who is deaf and blind, and we have been involved with disability issues for very nearly 40 years. One of the problems we have with the industry, as such, is that there are so very many people working within it who are well motivated but whose career paths are dependent on the disability budget and, as employees, they have first priority to its call. So the budget itself is drained—almost it is that there is a residue left for attending to the needs at the coalface. Part of this BAC idea is that, if we can get direct access to the funds, we can do the training ourselves, recruit and select ourselves, and manage it ourselves—that is, we do all the taxation matters; we do the BAS. We have to do that sort of stuff anyway so why can we not do the full monty and actually become a provider agency for Ben, for no-one else but Ben?

Senator BOYCE—You have set this up as a sort of company structure, an administrative structure—**Mr J Dainton**—No, it is not a company structure.

Senator BOYCE—Sorry, I mean as an administration structure. What governance would you see should be applied to that structure to assure the taxpayer that they are getting value for money?

Mr J Dainton—I thought I had covered that in my submission. Firstly, you mentioned governance and accounting. The accounting for the funding is almost automatic through the Australian Taxation Office. That is not a problem. It goes directly back to the Treasury. It is a short-circuit accounting process. We keep a set of accounts. Bruce, my son next door, has got his hand on that very efficiently.

In terms of governance, the word ‘governance’ seems to be applied to organisational structures. This is a sole trader. Why would you want a board of management for a sole trader organisation? Would every plumber and carpenter in the country need a board of management? This is a sole trader function. Ben is the proprietor, and the administrators are appointed by the courts. The public trustee oversees what you might call the governance of it because financial returns have to be presented to the public trustee every year under an evidence statement in the court. With regard to the governance, it is a sole trader business, so we govern it according to our need at the time. We do yearly planning and budgets, but the actual governance—that is, the day-to-day operations—is according to needs as they come up.

Senator BOYCE—I guess governance has come to include the processes of accountability and transparency as well. How would you demonstrate to the DFC that you are doing a better job than they are with the funds?

Mr J Dainton—I think we have both got a problem. We have already demonstrated that, and they do not seem to like it.

Senator BOYCE—Can you explain what you mean by that comment?

Mr J Dainton—Yes. The first three-months invoice clearly sets out the number of hours that we produced to serve Ben. We have covered all of the costs of employment, including compulsory superannuation and workers compensation, all of that stuff, and we can still give him a better service than he gets from any other agency at a much cheaper price. That has been demonstrated in the invoices.

Senator BOYCE—Can you tell me about the carers that you are training yourself.

Mr J Dainton—Yes. They are usually friends or people who are known to our friends. I do not think we would ever advertise. It would be only by word of mouth through people who either know us or Ben. We would invite them into the house to have a cup of tea and meet Ben and invite them to go for a walk with him for half an hour. If Ben does not like them it is the end of the process. They might not like him either. That is a first trial, then we invite them to tend him a little bit longer. We have written a training manual on Ben's care needs and we give them that. There are photographs. You can go bike riding and things like that. We do all of that.

Senator BOYCE—Once again looking at governance issues, you would be aware of the difficulties that carers as a group have in getting acceptance of the idea of paying a family member to be a carer. How do you satisfy DSC that the money you are paying to friends of the family to be carers is actually being expended on care?

Mrs Dainton—We have never employed family and have no intention of doing that. In a large community, but a small town, like Albany you see them working with other disabled people. I have coffee with the mums of these kids. You get to realise just how special some are, and there are others you would not invite to help with your family. It is really, as John said, word of mouth.

Senator BOYCE—So you have been doing some selecting along the way.

Mrs Dainton—We have, because Albany is very short on really reliable people. Of the ones who are already in the business, the reliable ones are usually spoken for. Our carer is being headhunted on a regular basis, so we need to assure Chris and Brian—the two prime carers—that we can employ them for the next six months or eight months, because for their budgets and their lives they need to know. At this stage, if the finance does not come through as promised, we may have to accept some of the other people who have asked them to come on board their team, which would be devastating.

Senator BOYCE—For some obscure reason, Mrs Dainton, all we can see is a slight amount of your hair and a very large blue—

Mrs Dainton—I am so sorry about that.

Senator BOYCE—No, it is not you.

CHAIR—It is not your fault.

Senator BOYCE—They have zeroed in on a particularly riveting part of the wall, so we are not getting your body.

CHAIR—I gather from what I am hearing in the background that there is something wrong with the remote control. We will just keep asking questions.

Senator BOYCE—We will just ask the wall some questions! I do not know if you can see us, but if our body language is not suiting what you are doing it is because we cannot actually see you anymore. We have no picture at all now, but we can hear you. That will teach me to criticise! There you are—you are back. I have spoken with other witnesses about the barriers to planning. You have this very big problem currently with DSC, but could you talk a bit about some of the other barriers to planning for when you can either no longer care or no longer wish to care?

Mrs Dainton—I do not know.

Mr J Dainton—The biggest barrier, as I see it, is the size and the complexity of the system. We find that, compared with the Commonwealth system, the state system is supercomplicated. The Commonwealth system in general is simple, it is straightforward, it is equitable and it is just. There is no justice in the state system, because there is no appeal system. What you get is what you have to accept, whether you like it or not, and there is no appeal. Not only that but you are not entitled to anything under the state system. So it gives them a free range to develop huge complexities within their own system that consume the vast sums of money. We have tried to sidestep that chain of command—that governance—and go directly to the funds. I have explained that to the DSC. I told them that, when I was in marketing, if someone wanted to buy something they went to the supplier. I thought that supplier was the DSC, but it seems to me that it is the Commonwealth. Our appeal is that if we can transfer our funding source to the Commonwealth it is going to be equitable, it is going to be fair and it is going to be simple—much simpler than the state system. If they could give us a quarterly budget that we would manage and account for in the way that anybody else has to, I would be happy about that, and I am sure that any future administrator of Ben's affairs would have a similar view.

Senator BOYCE—You said that the Commonwealth system was simple. Are you talking about the respite aspect of it or all the FaHCSIA and DoHA services available to someone with a disability?

Mr J Dainton—The simple part of that is that when we apply to the Commonwealth for funds, there are set rules, we are given a copy of the rules, and we follow them. We are not able to access respite care from the Commonwealth, as far as I am aware. But I am quite sure that if we could it would follow the same pattern as other funding sources. To get respite funding it seems to me that we have to go through this incredibly complicated process with the state.

Senator BOYCE—Are you talking about disability support pension, carer allowance and those sorts of things?

Mr J Dainton—All that stuff from the Commonwealth is simple.

Senator BOYCE—Is it those three: the carer payment, carer allowance and disability support pension, or are there other payments that come through—

Mr J Dainton—The disability support pension is also very simple for Ben. He is in receipt of that. We manage that for him and we account for it to the public trustee. That is tax-free income for Ben, but now he has a business we can put in a tax return for him. There are actually three tax returns he has to do and we put in all three. That accounts for his personal income, but his respite income, we were told, would wipe out his disability support pension. That is why we have had to go to the Commonwealth to get approval under section 35A of the Social Security Act. The Commonwealth has made it even simpler for us to access his respite funding without causing penalty. What we are now asking is that if we could access his respite funding, which I think probably is paid to the state—it is Commonwealth money administered under the state—through FaHCSIA, if they would provide us with a quarterly budget in advance, we could manage that and I would be delighted to pass them back an account of how it is funded and how it is managed. I know they will not do it, but if something could be done to reduce the barriers in the system—

CHAIR—Mr Dainton, I am just wondering: why do they say that the respite funding is taxable?

Mr J Dainton—It would have been taxable and it would wipe out his disability support pension because it would have been paid to a business that he owns. But under section 35 of the Social Security Act there has to be ministerial approval for it to be exempted from penalties, and we now have that letter.

CHAIR—So when you set up the business for Ben, you then sought the exemption from the Commonwealth.

Mr J Dainton—We did indeed.

CHAIR—Okay. I was not clear from your documentation. I did not quite follow the thread, but now I understand it. Thank you.

Senator BOYCE—You obviously looked at special disability trusts along the way for your planning. Could you tell us what was wrong with the special disability trusts, in your view?

Mr J Dainton—Number 1, it was very complicated. Number 2, it was difficult for us to access. But we did not have the wealth anyway that would warrant its use. What is even more important, and the reason it would not be suitable, is that, because we have been given administration over his affairs, I had in fact planned to form our own little trust. The court executive officer said, ‘If you get this you will not be forming a trust.’ I said, ‘What do you mean by that?’ He said, ‘If you form a trust, that means you are going to give his assets away to that trust.’ He said, ‘You are not to give any of his stuff away; you manage it for him.’

Senator BOYCE—Sorry, who made that comment?

Mr J Dainton—The executive officer of the court of the state administration tribunal. The point is that when you are administering someone’s affairs, you are not to give their stuff away. A trust would own that stuff. I raised the question of whether Ben could own a business, and they said, ‘Yes.’ So I saw the opportunity of doing what we have done. I was unaware at the time that we could do it, but once we were granted that administration, after 12 months I took the matter up with the public trustee. We had already done 12 months of accounting for him and shown that we were doing the job properly. I said, ‘We are going to start a business,’ and I told them what we were going to do, and I asked them if they would audit it. Apparently under the public trust act they are not allowed to do that, so we have had to appoint an outside auditor.

CHAIR—Mr Dainton, as you have said, you have put an awful lot of work into setting this process up and you obviously understand the complexity. I know you said the Special Disability Trust is complicated, but this seems to me to be quite complex as well. We understand a couple of other people have set up microboards. Are you in contact with others about what you have done, to try and help other people through this maze of complexity and bureaucracy?

Mr J Dainton—Yes, I have, and I have been invited to address Vela Microboards. They had a camp in Albany. They had their own lawyer down there and they asked me to talk to the lawyer privately. At first the lawyer also had trouble understanding what I was doing, but then she suddenly woke up to how incredibly simple it is. It appears to be complicated, because we are so used to everything else been complicated, but it is not. He simply owns his own business and it is administered for him by administrators. There is nothing complicated about that. It costs $90 for three years to register it, and yet because the Disability Services Commission could not comprehend the simplicity of it they have tried to make it complicated. He simply owns his own business, and all I have asked is that it be given an agency status so that his grant can be paid into his personal bank account or his business bank account for us to administer. What could be simpler than that?

CHAIR—I suppose the complexity is with the bureaucracy that has been associated with you having to deal with the bureaucracy, get the exemption et cetera. That seems to me the complicated bit, which would, quite frankly, put a lot of people off.

Mr J Dainton—It might.

Senator BOYCE—But it also involves you in being the employer, the hirer, the firer, the trainer et cetera, which is a role that some families perhaps would not want to have.

Mr J Dainton—Exactly.

Mrs Dainton—Yes, that is true.

Mr J Dainton—Rae says that, and I agree with that. It is a limited market. We would not be siphoning off a large part of the disability ‘market’, which is what it is. All we are doing is creating our own niche in that market. Anybody who has any experience at all in business, has employed people and knows something of the rudiments of accounting could do it. But they may not want to. We want to because we know Ben will get the best service available.

CHAIR—My last question is around getting a designated agency. Are you aware of any other of the two or three microboards, or any other structure such as yours, that has been designated an agency by the commission?

Mr J Dainton—No, I am not, but I do know of someone who has had an enormous difficulty with that particular issue with the commission. They spent a lot of money with lawyers and ended up having an argument with the lawyers and left them. I do not want to name them because it is not my place to name them.

CHAIR—That is fine.

Mr J Dainton—I am aware of others trying to do it.

CHAIR—I was not asking you to name them, necessarily. I want to know how common this is in Perth now or if any other company had been designated as an agency. I think we will see if we can write to the WA commission to ask them their thoughts about it, the experiences they have had and how many people are doing it.

Mr J Dainton—Thank you. I appreciate that.

CHAIR—We are finished with our questions. Are there any more points or comments you would like to make before we wrap up?

Mr Bruce Dainton—I would like to comment. You mentioned once, I think, the reporting structure for a sole agency. It would be quite simple. John mentioned it would go through the tax system and it would be just a simple balance sheet, some sort of template that a government could set up quite easily, to give to sole agencies.

The other thing I want to point out is that presently I am chairing the board. The DSC insisted when this was set up that it have a board. Realistically, it is a simple concept that only needs one person or maybe two people to operate the funds. They insisted on a board, so I was brought in. They insisted that a DSC person sit on our board, so that made it four. They said we needed an odd number on the board in case there are conflicts so we brought a fifth person in. I have had to chair these meetings.

Senator BOYCE—I hope the director’s fees are lucrative! That is a joke.

Mr Bruce Dainton—There was a promise of initial quarterly funds being put into the BAC account so it could be distributed to carers. That did not come through so we have had to put in an invoice, which I have assisted with. Once we put in the first invoice of $25,000-odd they paid it and since then we have put in a second invoice to say it is about $5,000. They are putting up barriers now to pay that. Presently we are operating out of Ben's personal account and John and Rae's personal account. The latest email from DSC says a person is going to get approval from their boss to pay the $5,000 invoice even if we do not submit a new funding plan that they require.

They also require assurances from Ben's Administration Company that support will be provided to Ben within $71,161. I don't understand why they need that and I do not want to get into some sort of email argy-bargy asking why we need to indicate assurances that we are going to provide funds within that amount. There is obviously a need to go to somewhere between $90,000 and $100,000 to provide the respite that is needed. So at the moment we are presuming they are going to continue with invoices rather than pay a quarterly amount into the account so it can be cash positive.

I am a bit frustrated having to deal with the DSC. I am doing it on a volunteer basis and we will continue because it has to be done. But I wonder—and John has already asked this question—if there is a feeling from the senators about there being support for approaching the Commonwealth so we do not have to deal with the DSC.

CHAIR—It is not something that we can decide here and now. We are gathering evidence at the moment and then will be reporting to the Senate. We will certainly take on board your comments and take them into consideration in our reporting. In the meantime, we are going to write to the DSC and ask them a whole series of questions around microboards and companies of the nature of yours, such as how they are paid, their decision-making processes and things like that, so we can see where the commission is coming from. We will also ask them, for example, whether similar agencies to the BAC once it is accredited are treated in the same way. For example, are they paid on invoice? Is your 'agency' being treated differently to any of the other agencies that supply support services? I cannot speak now on what the committee may or may not say until we have taken all our evidence and reported to the Senate.

Mr M Dainton—I want to make a comment about my personal experience with this state government through being a school cleaner and having an industrial campaign that has hit obstacle after obstacle, including the expense of $100,000 to bring in a special industrial lawyer. So when I heard dad say that the budget had been dropped from $91,000 to $71,000 I thought I know where some of that $20,000 went. It has been an extremely frustrating exercise for one particular union I know of that has tried to negotiate with good faith with the state government and has hit obstacle after obstacle. With this session here with Senators Siewert and Boyce I am feeling like there is hope. Thank you.

CHAIR—Thank you everybody, particularly everybody who has come up from Albany. I have done that trip many times. We really appreciate you making the effort to appear before the committee. Your evidence is very much appreciated.

Senator BOYCE—I have never done the trip to Albany. I think next time we should go and take the evidence in person.

CHAIR—You have my support there.

Mr M Dainton—Senator Boyce, being a parent of a child with down syndrome, do you live in New South Wales?

Senator BOYCE—No, Queensland.

Mr M Dainton—I beg your pardon because my wife and I are still members of the Down Syndrome Association New South Wales. Would you be a member of the association in Queensland?

Senator BOYCE—I am.

Mr M Dainton—There you go.

CHAIR—Thank you.

Committee adjourned at 5.01 pm