COMMONWEALTH OF AUSTRALIA

Proof Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

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

WEDNESDAY, 1 DECEMBER 2010

TOOWOOMBA

BY AUTHORITY OF THE SENATE

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SENATE COMMUNITY AFFAIRS

REFERENCES COMMITTEE

Wednesday, 1 December 2010

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

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

Senators in attendance: Senators Boyce, Moore 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 10.00 am

ROWE, Mr Geoffrey Francis, General Manager, Policy Research, Planning and Strategy, Endeavour Foundation

CHAIR (Senator Siewert)—Welcome. I would like to thank Tony Lanigan for helping to organise today's event, and I thank you all for coming. It is fair to say that this is the biggest crowd we have had at the hearings for this inquiry to date.

Senator BOYCE—Even though the others were in capital cities.

CHAIR—I have been asked to explain a little about the role of the committee. The Community Affairs Committee deals with all the health, disability and community services issues. Our role is hear reform recommendations from you, which we then release as a report, and we often then take on the role of encouraging government to implement the recommendations. Our specific role today is to hear your opinions and what you have to say on the particular issue of disability and ageing. I am sure many of you have seen the terms of reference, but I will go through them. They are to assess:

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?'.

We are very much looking forward to hearing your opinions on those issues. We will make our report to the Senate in the new year, then part of the process is for the community to take those recommendations and promote them to government for their implementation.

Today, as I said, we are very keen to hear your opinions, and we will have a community forum this afternoon that I am very much looking forward to. I would like to acknowledge the member for Toowoomba North, Kerry Shine MP, who is present. Also, the media is here and I would like to check that everyone is okay with that. If you do not want to be filmed, let us know, please—although we do not usually find that that is an issue, I have to say.

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

Mr Rowe—That is right.

CHAIR—We have your submission, which we have designated No. 9. I invite you to make an opening statement and then we will move to questions.

Mr Rowe—Thank you for the opportunity this morning to give evidence to the Senate Community Affairs References Committee. The issue of disability and ageing is very important to Endeavour as an organisation, the families of the people we support and, indeed, the individual people with disability we support. I want to briefly highlight some of the matters that we raised in our May 2010 submission, add some developments in thinking since the lodgement of that submission, given that that is now six months ago, and also, I guess, reflect the changes that have been made to the terms of reference.

Endeavour, as you know, is a very large non-government disability service provider. We support about 3½ thousand people with a disability across Queensland and New South Wales. We are an organisation that turns 60 next year. We started as an organisation supporting children, largely in the area of education. It was set up by a group of mums who found that the education department of the day was saying that their children were not able to be educated and could not be sent to school. That set the tone for Endeavour in that we are an organisation that tends to provide services to people where those services are not available in the mainstream. That probably also sets some of the philosophy about what we believe. One of the core things that we believe is that people with a disability should have the same rights and access to services as the rest of the members of the community. When we are talking about aged care or the ageing of our clients we would hope and expect that they would have access to similar services and resources as you and I would have as we age. Our philosophy is about supporting people to lead an ordinary life. The term 'ordinary' is a very powerful term in that it gives a broad scope. It is about personal hopes, wishes and desires. I will leave it there.

One of the points I wanted to make is that, from my perspective, one of the best ways of supporting ageing carers is by providing support to their sons and daughters. During our organisation’s travels over the years we got many examples of ageing carers who are absolutely terrified of dying—not so much the dying experience; the issue is, ‘What will happen to our sons and daughters when we die?’ I am aware that this inquiry looks not so much at services but at planning, but I need to give you the Queensland context so that you will understand some of the things we are saying. The expenditure on disability services in Queensland represents about two-thirds the national average per capita spend. That means that, when you have a disability and live in Queensland, there are fewer services available to you than if you lived in New South Wales, Victoria, WA et cetera. Therefore, when those services do not exist it is very hard to plan to access those. Because of that comparatively low-level expenditure, one of the cultures that has been established in Queensland is that it is often the urgent and critical issues or situations that are addressed by government and by government funding. Therefore, to some extent the best thing you can do as a carer—and I may sound slightly flippant—is die, because then the chances are that your son or daughter will get a service. That is not a very good solution. Certainly, as a service provider, we can say to people, ‘When you die, the chances are that the government will intervene, funding will be provided and your son or daughter will be looked after,’ but that is not particularly reassuring for a carer or a parent: when you are gone you do not really know whether those services will be available.

What we really need is some strategies in place to provide a capacity for people with a disability and their families to lead to the ordinary life that we aspire to. As an organisation, given the constraints within the disability system, as I mentioned, the focus has been on improving access to the mainstream service system. I will talk a little bit about some of the stuff that we are starting to do in trying to link in with the mainstream. I have to make the point that Endeavour is a large provider and probably has a lot more resources and capacity to interface with the mainstream system than a lot of other disability service providers. While I want to talk about what we are doing, it is not a strategy that necessarily can translate across to other service providers. I am looking for some other external support in opening up the mainstream service system.

One of the things I want to highlight before doing that is that ageing often happens earlier for people with a disability. That depends on the type of disability. We certainly know that people with Down syndrome experience some of the signs of ageing in their early forties. So, when we talk about accessing the age system, we are talking about 20 years before the eligibility criteria kicks in. There are lots of issues associated with that.

Endeavour is actually Australia’s largest provider of supported employment services for people with a disability. We employ more people with a disability, I understand, than anyone else in Australia. We support about 1,850 people with a disability. Currently we know, from talking with our clients, that about 12 per cent of those people do not really want to be in employment anymore; they want to retire. Unfortunately, there are not options available for them outside the workplace, in terms of their support, their recreation and their socialisation, for them to retire, so we are seeing people staying in our supported employment services, our ADEs, much longer than they want to. Indeed, one of the unintended consequences of this is that our younger cohort of people who are looking to move into employment cannot get into employment because there is that group at the other end who, literally, will not leave, do not want to leave or cannot leave.

Looking at some of the stats and the age group of people, we are seeing that, by 2018, potentially 46 per cent of people in ADEs will be at the point where they want to retire and will not be able to retire. There are some pretty ugly statistics. If we can do something to address that, it would certainly have a big influence on and make a big change to their lives and their carers’ lives. It would also have a big impact on younger people with a disability who are looking for employment, particularly in that ADE type environment.

Briefly, as I said in our submission, we have certainly experienced difficulty in supporting people with a disability to access the aged care system. Rather than just saying that this is a problem, we have tried to be a little bit proactive. At the moment we are developing some partnerships with aged care providers to support them, train their staff and support that transition process. Effectively, we are taking a case management approach to the transition of people with disabilities into the aged care system. That is something very different to the normal mainstream system, in that when you and I age the aged care system will have a number of transition points which will allow our access into it far more easily than what happens when you have a disability. I guess, effectively, I could be saying that people with a disability are to some extent discriminated against when it comes to accessing that system.

We are trying to manage the assessment process for entering into the aged care system. Again, as I highlighted in our submission, the current tools that are used for entering the aged care system do not really work for people with a disability. When you look at functionality changes or capacity changes and you look at a measure of ‘could you do this last week and can you do it this week?’, if you could do it last week but you cannot this week that is a tick in the box. Under the current regime, if you could not do it last week and you cannot do it this week that is not a tick in the box, because things have not changed for you.

We have been starting to link with the University of Queensland GP superclinics that are being established and are looking at using the comprehensive medical assessment that is available under the Medicare system to try and get a tracking of people’s capacity and people’s health. My understanding is that that comprehensive medical assessment is one of the tools that is used for entering into the aged care system. As a disability provider we are saying that we need to be proactive, to start having our clients use that system on an annual basis so that there is some tracking. We are also looking at the introduction of electronic health records so that we become the owners of that medical information so that we can present that as part of the evidence for people’s transition into the aged care system.

I probably do have to say, while I am talking about access to the aged care system for people with a disability, that I am really only talking about the people for whom that is an appropriate option. We certainly are not advocating that people with a disability should be put into the aged care system because they have a disability. It should be around the issues associated with their ageing. We are also looking at similar processes in accessing the aged care packages. Again, as people age the most appropriate option is to support them to age in place.

In respect of the cohort that are looking at retiring in the absence of other options, we are starting to explore whether there are some possibilities to do some partnerships in retirement villages—and organisations like Endeavour have some assets. If we can partner effectively with some of the retirement village providers, we believe that we can provide an option for some people to move into a retirement village arrangement, where, because of the density of living, they will get some support during the daylight hours that would not be available in the broader community once they retire.

The other thing I want to put on the table in closing is to request that the committee explore the viability of recommending development of disability bonds, for want of a better term. When you look at what is out there in the marketplace at the moment, when your child is born you can get an education bond and you can make tax-effective payments into that to help assist with the cost of your son or daughter’s education when they move into the school environment. In the same way, if there were a similar sort of strategy for people with a disability—for families that have the capacity—they could make tax-effective contributions, much in the way that superannuation works, towards the cost of the care or accommodation of their son or daughter in the future. That may encourage some people to use that system and, as their children age in life, to feel that in the absence of other support being available there will be some financial resources available for their son or daughter to be supported. That is all from me for the moment.

CHAIR—I was remiss earlier. I should also have acknowledged the Toowoomba regional councillor Bill Cahill. Welcome.

Senator BOYCE—I am interested in the idea you put to us at the end of your statement about the disability bonds. Could you talk a bit about how that would work with special disability trusts and a potential national disability insurance scheme.

Mr Rowe—I will endeavour to answer that one. The national disability insurance scheme is something that providers like Endeavour care organisations and service user networks are very excited about. They are very hopeful that that will come in and that it will provide a solution to the current system, which is effectively broken. That is not a given. At the end of the day, one of the things that we are very mindful of is that we are asking the Australian community to sign up for another big new fat tax. Potentially that is the way it may operate. Certainly we are hopeful that an NDIS will happen. In the absence of that being guaranteed, or in the absence of knowing the full scope of that—and it is probably hard to imagine in our current world that an NDIS will meet all of people’s needs—something like the bond idea could, if it were set up in the right way, either look at providing support services to a person or look at purchasing accommodation, because disability housing, while it is available through the public system, is not guaranteed, is not always there when people want it, and is not necessarily as flexible as it could be if people would like to move around. The thinking that we have done around the idea of disability bonds is that it is a way of providing a pool of money, a pool of resources. If an NDIS comes in and if it meets people's needs, that bond arrangement could meet some of the gaps in those—that is without knowing the full scope.

Senator BOYCE—What are the impediments at the moment for a family to establish a disability bond?

Mr Rowe—My understanding—certainly the feedback I get—of the attempts that people have made to date in setting up some sort of trust is that there are not the tax concessions that people would like and that there are impacts on the individual's disability support pension, if that money is attached to them. What I am suggesting in the bond situation is that it is something that does not impact on the individual's DSP and is tax effective. If you look at the way superannuation has gone over the years, it is not necessarily something that an organisation like Endeavour or an individual mum or dad would have to run. Potentially the marketplace would pick that up as something that they could pick up and run with.

Senator BOYCE—And the problem with current insurance type bonds would be that they count as assets for the individual. That is the main problem with them.

Mr Rowe—Absolutely.

Senator BOYCE—There have been some changes to the special disability trusts which have freed them up a bit in the last couple of weeks, so hopefully that will lead to an uptake there. One issue that has come up in our hearings in Sydney and Melbourne has been that it is very difficult to plan in the absence of anything concrete to plan for. You can have all the dreams you want, but if there is no accommodation available a lot of families are thinking, 'What's the point?' Could you talk us through accommodation and how easily it is gained in Queensland.

Mr Rowe—In my opening comments I tried to say that one of the issues is that planning is a futile exercise in the absence of services. Endeavour as an organisation provides accommodation for about 900 people with a disability across Queensland. The bulk of those people live in accommodation that is owned and provided by Endeavour Foundation. Some of that is a reflection of history. Some of that is a reflection of the lack of affordable options that are available either in the mainstream community or within the public housing system. Queensland certainly has a long housing waiting list. From Endeavour's perspective, it is a system that we have not used well enough, purely because, when you put your name down, if you have to wait five years or six years it seems to be a little bit silly. Often people's needs are immediate.

Senator BOYCE—In New South Wales we were told that you put your name on a register, not a waiting list, and then the neediest get served first. So there is really no hope that they will ever deal with anyone except people in crisis. Is that the situation here?

Mr Rowe—I believe it is very similar to that. There has been a real growth in community housing options and affordable housing options. I think as a disability sector that is an area that, in the absence of the public system providing, we have to explore more. But it is very early days.

Senator BOYCE—The other question that has been raised is the difficulty of getting government services provided to privately owned accommodation.

Mr Rowe—I would not have thought there was a great deal of variation in Queensland. The biggest difficulty in Queensland is for you to get those support services from government. Where you live is almost irrelevant. Certainly one of the pressures for people with a disability is for them to live with other people with a disability, purely because of the inadequacy of current funding and the need to share support and share resources.

Senator BOYCE—Choice is just rhetoric, not a reality, because if you do not take what is offered nothing will get offered for another four or five years.

Mr Rowe—That is potentially right.

CHAIR—Can I just clarify that. This is a really strong point that came up in New South Wales. A number of parents were talking about setting up private share accommodation. The stumbling block was that the New South Wales government, because of the way the system was set up, would not provide them with the support services into that home. What you are saying is that that does not happen in Queensland. If you set up that sort of shared accommodation, you can still attract the support services, the packages.

Mr Rowe—You certainly can still attract the support services. The issue will be that the trigger in Queensland at the moment is 'urgent and critical'. Historically, under some of the schemes that have been operated by the state government, if you were waiting outside the front gate of a nursing home you were seen to be absolutely a top priority because you were at risk of entering a nursing home. If you actually went in there, you would drop off the priority list because you were seen to have some support—not necessarily appropriate support but some support. Potentially one of the triggers here may be that if you are with a group of people that might lower your priority because you would be seen to have some stable accommodation, if not support. I am probably grasping at straws on that one. The trigger for support services is urgency and crisis.

CHAIR—It is the same issue in New South Wales: it is around crisis.

Senator BOYCE—I want to ask you some more details about your ageing response strategy. I am assuming that the partnership with aged-care providers is part of that strategy?

Mr Rowe—Absolutely.

Senator BOYCE—Can you give us some more details about what you are doing there.

Mr Rowe—I am not quite sure about the appropriateness of identifying some of the private providers that we are talking to. We have talked to a couple of the main providers in Brisbane as a starting point. Some of those are church based providers of aged care. It is about saying, ‘This is our issue.’ We have a cohort that, moving forward, will be looking at formal aged care. We want them to be supported in the best way that they can be. We are happy to assist in that transition; we are happy to train new staff; we are happy to provide support during the transition so that people make an effective transition into the aged care system. As I mentioned, we are also looking at healthcare records and needs records that need to be available to assist that transition into the aged-care system.

About 10 years ago, Endeavour was successful in getting about 20 community aged-care places to support carers more so than individuals with a disability. We are providing aged-care support to carers to continue to live in the community. By default, by doing that they are able to continue to support their sons and daughters in a community situation. We have applied every year, until the most recent year, for additional places and have been knocked back under the aged-care funding round. This year we just made the judgment that this is a waste of our time and a waste of our energy. But, for the people we are supporting, the CAP and EACH packages work really well.

Senator BOYCE—And they are ageing in place—

Mr Rowe—They are absolutely ageing in place.

Senator BOYCE—in their supported accommodation or wherever it is—

Mr Rowe—That funding targets carers, so it supports carers to continue to live in their home and support their son or daughter with a disability. I talked to some of our staff during the week about this hearing and they made the point that a lot of our clients who are ageing are starting to move into the carer role for their aged carer, which is a real change to how it has historically been. It demonstrates the lack of support that is available for people to continue to care as they age.

Senator BOYCE—Are these people all 65—the ones you are talking about moving in? Perhaps you could talk about the under 65 and over 65 issue.

Mr Rowe—One of the things I was trying to highlight in our submission is that we are looking at a tsunami coming. It sounds like a dramatic term. At the moment Endeavour supports about 90 people over the age of 65. If you look at the group of people in the age group 60 to 64, there are 177 people. If you look at the cohort in the 50 to 59 range, we have 765 people. If you look at the 40 to 49 age group, we are talking about nearly 1,100 people. While we are talking about 90 people over the age of 65—and that is where we are focusing our energy and attention—our intent is that, once we have been able to address the needs of the over 65 age group, we will look at the 60 to 64 age group. In terms of gathering some of the evidence, we will move down to the lower age groups so that we are not confronted with the battles that we have at the moment when someone turns 65. We have people in their forties with early-onset dementia. Typical aged-care issues are alive and well and in their lives. They are a cohort that we are struggling to support. While there has been demarcation—the Commonwealth looks after funding for people over the age of 65; the state looks after funding for those under 65—the closer you get to the magic number of 65 the less interest you get from the state, and you certainly do not get any interest from Commonwealth funding arrangements until you have hit that magic birthday.

One of the things we raised in our submission was that we know that the aged-care system has a different set of criteria for Aboriginal and Islander people because of the well-established research about early ageing and a shorter lifespan. We would contend that that is a similar issue for people with a disability and there should be some flexibility around the magic age of 65, particularly with the ageing in place stuff and continuing to live in the community. Again, we are not advocating that, because someone is ageing and they have a disability, they should be in nursing home care. That is only about medical care.

Senator BOYCE—We heard evidence yesterday about a service provider in Newcastle that runs ADEs that was fundraising so that 12 people could cut back their work and go to day centres et cetera just so they could be semi-retired. The only way for them to be out of the workforce was for this organisation to go out and bake cakes and things to provide the funds to do that. What happens in Endeavour with people who have to retire? Where do they go?

Mr Rowe—One of our services is at Southport, where we have a separate work area and a capacity to support that. I think at the moment there are about 15 people who, rather than working in the main part of the ADE, do far less complex and simpler jobs and are supported within that environment. That is far from ideal.

Senator BOYCE—They cannot simply stay home and watch TV if that is what they wish to do?

Mr Rowe—By and large, you are talking either about people having an ageing carer who does not have the capacity to provide that 24-hour care for their son or daughter or about people who are supported in an accommodation service somewhere the viability of whose services is contingent on people being away during the day. One of the things Endeavour did earlier in the year was to put a transition to retirement proposal to then Parliamentary Secretary Bill Shorten saying, ‘This is a major issue; these are some ideas; these are things we would like to pilot.’ Just before the election we received advice that there were, I think, two pilots being operated in New South Wales and the ACT. Thank you very much; we will wait to see the outcome of that.

It is still a major issue. If you go back five to eight years, at that stage the Commonwealth identified a large number of people within the ADEs who did not want to be there and wanted to retire. They set up the targeted support program. That provided a small amount of money for those individuals to transition out of the ADEs and into more appropriate community placements—but that was a one-off blip in time, unfortunately. Those people are certainly still being supported. Endeavour supports probably about 60 people here in Toowoomba who were in those ADEs, did not want to work and are now supported in a day service environment. But they were, to some extent, a lucky cohort who managed to find that one short-term change in policy.

ADEs are really struggling because part of the premise of the funding of ADEs is that they have to be real jobs, real businesses and real wages. How do you operate a real business and provide people with real wages when they are not productive and do not want to be there? That is something we struggle with regularly and, I guess, we are quite concerned about moving forward. The viability of the businesses we operate is based on people being productive and producing goods that are there for sale. If they are unable to produce goods, there is still a minimum wage that we are required to pay people, so we are paying people who do not want to be there for not being productive while we have a cohort ‘standing outside the doors’ who do want to work and cannot. It is madness.

Senator BOYCE—Are you able to provide us with a copy of the transition to retirement document?

Mr Rowe—Absolutely.

Senator BOYCE—Thank you.

Senator MOORE—Regarding the last group you talked about, in relation to the need to move beyond the ADE employment, you mentioned earlier that if the carer died they would probably find something to do. In your experience, what exactly is available for those people who no longer have the support of a carer or can no longer be in an ADE?

Mr Rowe—Certainly my experience is that, when a carer dies and a person with a disability has no support options, what is now the department of communities—formerly Disability and Community Care Services Queensland—will intervene to provide emergency and crisis funding to agencies like Endeavour to provide support to that individual. Eventually, that emergency and crisis funding turns into recurrent funding. It sounds pretty clinical, but that effectively is what happens.

My experience working in the sector for many years is that I know that people with a disability are overrepresented in the child protection system, in the criminal justice system and in the health system, and that is all about inappropriate placements being available or the services that they need not being available. At the end of the day, we tend to go for more expensive options rather than for supporting people. I am probably wrapping a few things up when I talk about child protection. It is generally about parents being unable to cope and it is about relinquishment. In my mind, if a small amount of spend were put in there early to support carers to continue to care and provide respite, that would happen less. In terms of the criminal justice system, if there were day services and other options available for people, they are less likely to get into trouble. The health system is often such that people say, ‘There is nowhere else to place someone so we’ll put them in hospital,’ particularly in rural Queensland, where there are fewer options available. Often hospital is the catch-all or the place of last resort. Those options, particularly the health systems, are very expensive options, in the same way as nursing home care is an expensive option when other options could be available.

Senator MOORE—They are expensive options to government rather than individuals, though. We are saying that inevitably it comes back to expense to everyone, but the options you were describing are all government expenses.

Mr Rowe—The ones that people end up with by default are the ones for which the government is providing support and providing it expensively.

Senator MOORE—On the income aspect, when you made your original comments about people who were in ADE employment and the funnelling effect, that could be applied to anyone in the community in any work, so I am trying to home in to make it specific for people with disabilities so that people who are at the stage of not being able to work, or one group who simply cannot because of other things happening with ageing, are unable to continue with the activities linked to work. There are people who do not want to be anywhere. It is actually the options that are available. In terms of the options that are available in this part of the world, are day support services available apart from the ADE employment aspect?

Mr Rowe—My experience is that most of the day service options across Queensland are absolutely full. You cannot go to a service and say, ‘Have you got a space?’ People say, ‘Yes, come in.’ From Endeavour’s perspective, one of the things we are looking at over time is staff-client ratios. When I look at some of the staff-client ratios that we operate with for our day services across the state, they are very poor. They do not meet people’s needs, but we have tried to be accommodating over time in terms of taking people on. We know that as our clients age their support needs go up. So those staff ratios are just not working and are not viable. Something has got to give. For a number of our day services, as people die or leave our services we will not be backfilling. We will be trying to get a better client-staff ratio than we currently offer.

I have talked a lot about government funding and government resourcing. I do have to say that, as an organisation, Endeavour’s annual budget is about $150 million. We receive approximately half of that from government and the rest we have to generate ourselves. It is not all about government doing and government providing. Agencies like Endeavour and others make substantial contributions to the support requirements of people with a disability.

Senator MOORE—Has that ratio changed over the years?

Mr Rowe—For Endeavour that level of government funding has probably increased, and that has been a reflection of the increased difficulty in fundraising from the public. Some of that is about changing community attitudes to fundraising, and some of it is about a lot more competitors in the fundraising marketplace.

Senator MOORE—What is your funding now, state-federal? What is the percentage? It is not in the submission.

Mr Rowe—We receive about $58 million a year from the state government and about $20 million from the federal government.

Senator MOORE—Is the $20 million from the federal government the program part of it?

Mr Rowe—It is for the ADEs, but, if you understand how ADEs work, it is about support staff to enable people to work. It cannot be used for wages.

Senator MOORE—Does that federal funding include the money you talked about earlier in terms of support for aged care packages?

Mr Rowe—Yes.

Senator MOORE—It does include that as well?

Mr Rowe—It does include that.

Senator MOORE—Can we get a breakdown on that funding from you? It is just to see, in terms of current federal funding, what is the percentage and what it is used for, because the aged care packages are particularly interesting in their options for people. Also, they are focused on the carer rather than on the person who identifies with a disability.

Mr Rowe—Off the top of my head, I would think that the aged care funding that we get would be less than $400,000 a year. It is not a big number.

Senator MOORE—It would be nice to have that broken down. Do you get other individual caring packages either through the state or federally?

Mr Rowe—Certainly through the state government we do, and that is included in the $58 million figure.

Senator MOORE—We would like to know more about how the linkage with the doctors through the UQ GP clinics works. Rather than take up time now, can we get the answer to that on notice as well. Also, how long has that been going and what is the plan for that project in the whole aspect of ageing? That information would be very useful.

Mr Rowe—It is certainly very early days, but I am happy to provide you with that.

CHAIR—I am interested in the assessment process. You said that you had been working with a comprehensive medical assessment process through the superclinic. Other people have been looking at ACAT, and I am taking a particular interest in ACAT versus some other assessment tool. We have been talking to other witnesses about other assessment tools that look at early-onset dementia and early ageing. I am wondering whether you have explored the use of other assessment tools and whether you have talked about that with government.

Mr Rowe—Endeavour has recently brought online a person with a long history in health and aged care to help untangle the situation. His advice has been that the comprehensive medical assessment is one of the key tools that is used as part of the ACAT process. So if we can embrace and use that more effectively it will give us a better ‘in’ within the ACAT system.

Endeavour was involved in the development of the CHAPs program, the comprehensive health assessment program, with Professor Nick Lennox, and we have been rolling that out for all of our clients over a number of years. It is about looking at people’s healthcare needs. My understanding is that using it as evidence within the ACAT environment is not as robust as using the comprehensive medical assessment. That is why we—

CHAIR—If you could provide us with some more information on that it would be extremely useful. One of the other issues that have been brought up is benchmarking somebody before they start ageing, certainly early-onset ageing, and the fact that the ACAT process is not picking that up. So any additional information you could provide us with would be very useful.

Senator MOORE—Mr Rowe, were the questions that Senator Siewert was asking the kinds of things you were discussing with the UQ? I was hoping that, particularly, that last point about how you actually benchmark and work with the existing entrance assessment was one of the aspirations of the project. Is that right?

Mr Rowe—Yes. It is certainly about trying to use the mainstream. We are starting with the UQ GP superclinics because we believe that they are sympathetic to what we are trying to do, and they certainly have a level of expertise in disability which is not necessarily out there in the mainstream. We are certainly trying now to influence the training of doctors so that they understand, particularly, intellectual disability a lot better than the mainstream do. I am sure you will hear around the country that the medical system has difficulty particularly with people with an intellectual disability, and that is around communication.

Senator MOORE—Certainly one of the things that we have heard over a number of years is that individual families have individual doctors who understand the family. The ageing of doctors is an issue in the country as well, and when that doctor is no longer there it has been very difficult for families to find someone who understands their issues. Is that something that your families talk to you about?

Mr Rowe—Absolutely. In Queensland we have just had restrictive practices legislation introduced, and as part of that it is required that we look at reducing any form of restrictive practice that has operated. For us it has meant that there have been nearly 400 clients who have had to have their medication reviewed to look at whether the medication is about reducing a person’s behaviour, changing a person’s behaviour, or whether it is treatment of a medical condition. It has been an enormous process trying to link with the health system, with the medical system, across the state to get them to understand the particular needs of people with an intellectual disability and why you would be looking at responding to their medical needs rather than to their behaviour.

Senator MOORE—I do not know that legislation, so we will follow up on that. That was a particular issue for people who actually have intellectual disability. Was that understood by the government? What happens is that they tend to have ‘one size fits all’ legislation. Was the particular impact on families with disabilities taken into account, to your knowledge? We will follow up with the government but, to your knowledge, was that something that was thought about?

Mr Rowe—Certainly that piece of legislation referred to was specifically for people with an intellectual disability.

Senator MOORE—Hopefully people were consulted about that.

Mr Rowe—It came out of the Carter report, a particular Queensland investigation. I am not sure that people were consulted as well as they should have been. The medical system certainly was not primed to respond to that legislation.

Senator MOORE—We will follow up on that. It is something I did not know about. Under the health and hospital reform, there are going to be changes of responsibility in aged care and disability care and those things. Your area crosses over right in the middle. Has Endeavour been involved in talking with government about those changes? I know it is at a very early stage but have you had any opportunity to talk with government about the particular issues that your client group and your members know best?

Mr Rowe—We are certainly starting to talk to government—at the federal level probably not thus far, but certainly at the state level, through both Queensland Health and the Department of Communities.

Senator MOORE—So it is actually on the agenda?

Mr Rowe—Absolutely on the agenda. It has been an issue of frustration for many years, that magic number 65. I guess the optimist in me would say that hopefully this will make life easier for people. We will wait and see.

CHAIR—We have run out of time, as we always do. We have given you some homework. If you need clarification about what you have agreed that you will provide us with, we can provide that through the secretariat. Thank you.

Mr Rowe—Thank you.

[10.47 am]

HORAN, Mr Michael James (Mike), Member for Toowoomba South, Queensland Parliament

CHAIR—Welcome. I understand you have been given information on parliamentary privilege and protection of witnesses and evidence, and I am sure you know the procedures really well. Do you have any comment to make on the capacity in which you appear?

Mr Horan—I am appearing before the Senate to give you some idea of the problems experienced by elderly parents who have disabled children and who are themselves getting older, in particular the need for accommodation and supported care. I am providing you with a verbal submission only, really to convey what is happening in this regional city to which so many people gravitate.

CHAIR—I invite you to make that oral submission and then we will ask you some questions.

Mr Horan—Thank you to all of you for coming here to our regional city. Toowoomba is a city that by 2030 is predicted to have a population of just on 200,000 people in a 25-kilometre radius from the centre of the city. As it is a regional city serving much of south-western Queensland, northern New South Wales and South Burnett, often people gravitate to Toowoomba if they have a particular difficulty within their family. There would be many families who have come here over the years to try and access services because they have got children with a disability, as well as the people who live here in this city.

Your inquiry is specifically about elderly families or elderly people and their elderly disabled children. We often say the mark of a nation is how it cares for its aged people. In this case it is aged people who have also provided an enormous amount of love and care for their disabled children throughout their life. In most cases these families have had to sacrifice having two incomes because only one has been able to work and one has had care for the disabled child, and they are getting to the stage now where they want to feel confident, having raised their children and themselves getting on in years, that when they pass away there will be accommodation and care for their children. It really is one of the most important things that we should be doing and it is probably one of the most important yardsticks of us as a nation that we can care for these families.

TIDSA, the local group, have estimated that there are just over 7,000 people with a disability in this region, and that is backed up by figures that they have got from a study and a report done by the University of Southern Queensland. So there is a big need. Other regional centres like Rockhampton and Townsville would probably be in a similar position to Toowoomba in that they are the centre for a great big regional area and people gravitate there for the services.

I think there are two aspects to this. One is the capital needs for housing and the type of housing. The other one, alongside that, is the recurrent costs and the ongoing costs to provide the care that perhaps in the past has been provided free for the nation by the parents. So there are those two aspects of cost. Also, we have got to look at the range of disabilities. Often in our electorate offices, and it may be the same for you too, we come across cases where families have a child with a very difficult disability to deal with—for example, severe autism. The parents are able to care for the child, but when the child gets to 16, 17 or 18 they can become very difficult to handle, and there are other kids in the family and so on. Then the issue is where that child can be placed where they are secure and safe. It is sometimes very difficult for those around them. In the main we are talking about those with mild to medium intellectual disability who are being cared for at home by parents right through to perhaps age 40 or 50, and the parents are well and truly getting on. The issue is about where they can live and how they can be cared for.

In Toowoomba there are a couple of examples of where people with an intellectual disability are living very successfully in a house in the suburbs. There is one example I know of out here at Middle Ridge, where three men, probably in their 40s—big, strong men—are in a nice house in a normal suburban street. That is working well, with live-in care 24 hours a day on a rostered basis. The Catholic Church run a couple of houses, one for four men at Harristown and another one for some ladies in another suburb. They run well and successfully.

I think there has to also be an approach to looking towards villa style accommodation. There is quite a trend in our community today where, for security reasons, many people want to live in a little gated community, perhaps of six or eight units. Many people like to go into a retirement village which has security, because there is a gate that is locked at night and emergency call to security and so forth. We are seeing a proliferation of those. I think we have to get away from the word ‘institutionalisation’. We have to get a term that is more modern and contemporary, where we can provide safety and care for people who need that safety and care and who also need to have as much individual freedom and opportunity to enjoy life to their maximum capacity.

There have been some proposals put forward by TIDSA which I think really should be looked at by this committee. It is along the lines of a little villa—perhaps four duplexes and one central building for the carers. That way you can provide accommodation that is very pleasant, that is safe and modern and that also can mean that perhaps we can get more accommodation for every so many million dollars. I think it provides individual freedoms and opportunities to the maximum potential of the residents. It can provide them with some company, with other people about. I think it is a good model to look at as well as the individual house within the suburbs.

The reason that I say that the villa system could be very satisfactory is that you can build absolutely delightful, pleasant little villas that have everything in terms of the environment, proper design for wheelchair access and bathroom access, a nice garden atmosphere and so on. I am thinking of the cost. Whilst I made the point at the start that it is the mark of a nation to be able to look after these elderly families, at the end of the day it always comes down to money. I think one of the big costs is going to be the recurrent costs of carers. Governments can often find capital to build a certain number of homes, but if with each of those homes go a certain number of carers 24 hours a day, seven days a week, public holidays and so on, that cost gets added on, which can be huge.

I think the villa style can provide a pleasant environment. In the regional cities of Queensland and elsewhere in Australia there are many very attractive areas where these villas could be built. All the time around the city certain properties are being bought up. I do not think the villas should necessarily be on the outskirts of the city. They should be within the city so that there is a real feeling that it is part of the city and so that access on a little community bus or minibus to activities in town can be relatively easy.

Parallel to that, there is a real need for emergency/respite accommodation. As families age, very often a stroke or a heart attack or something can happen and all of a sudden the need goes from being ‘some time in the future’ to ‘right now’. There needs to be a formula developed where there might be one duplex per so many intellectually disabled residents that is kept for emergency care and for respite care. Very often it just might be that someone needs to have their child stay somewhere for a short while.

I think a lot of parents who have provided this care, lovingly for a long time, perhaps feel they would like their child to be able to move into independent type living whilst they as parents are still capable of being able to help them move, of being able to bring them home for weekends or Christmas or family functions—while they are able to do that—not late in life when they are finding it very difficult to do those things and to be the support that they once were. So I think there should be a target of an age by which to try to achieve that. The whole thing should be kept as simple as possible.

To get good value you really need a highly commercial or practical board to run this. In this city I could give you names of people that could drive this and make it happen. It is the same in other cities of Australia. You would have a couple of builders on it that really can make things happen. You could have a budget of X amount to build villas, and you could have local knowledge, with people who could really get absolute value—who could get the jobs done on time and get the concrete poured so that everything happens in the right way in the construction. Also on the board you would want to have some people who are dynamic in being able to make things happen and in being able to listen to people and understand—in other words, good civic leaders, business people of some sort. Then I think you would want some representation of families who have had or have children with disabilities so that you have got the intimate knowledge of what is needed in the houses.

So I would see a type of board like that, perhaps, for the state to try and keep costs down. But the urgent need now is real expertise in dealing with that budget with no waste, absolute efficiency, the maximum benefit in buying land and building and the right design of the places so that we can get as many roofs over heads as possible. I could not give you the exact figure, but I know from people coming to see me that the need is urgent. They are getting fearful that the day on which their health deteriorates may be tomorrow and they are fearful that, after all the care they have put in, their child might be left almost wandering in no-man’s-land, wherever they go to.

Senator BOYCE—We are talking about the fact that people with disabilities have often lived with their families for all of their lives. The rest of us would anticipate, sometimes not with success, that our children would be moving out some time between 18 and 40.

Senator MOORE—Several times!

Senator BOYCE—Yes, several times! And yet this is just a pipedream, it would seem, for the majority of parents with children with disabilities. Is it that the planning needs to start early? Is it the policies that have created that problem? Since deinstitutionalisation, there has been almost a culture that says parents will provide the care for people with disabilities until they cannot. What do we need to change?

Mr Horan—I think you need to set an approximate time when you endeavour to provide a home, care and an individual life for people with an intellectual disability. The difficult time for families, first of all, and where the children need to stay with their families if possible, is when they hit the 18 mark. They have finished at, say, the special school, where there has been activity and opportunity, and from there they have to move on. Do they move on to some sort of employment, such as Endeavour provides? That time is probably a time when they need to have their parents' support. It is hard to put an exact date on it all. I would say that by the time someone is 30 their parents are most likely going to be anywhere from 60 to 80, so I think that is about the time when they should be looking at establishing them in a home—and a home of their own where they can build and forge a life.

One of the really important things is to provide the opportunity early enough—there are many and varied cases, so you cannot say exactly when it is right—that the parents are not so old that they cannot help in the process. Even when your kids leave home at 18 or 19, you go through grief. You miss them around the table. But there is a time you are able to help your kids. When they are moving into units or flats or starting another life, you can be around for a while. That is really important.

It would be good if your report could look at the capital type of construction, then at the recurrent costs and also at approximate targets to be able to do it. When parents get into their sixties and seventies, they would be starting to get really concerned that if something happened to them quickly they would not be in a position to help. The difficult time is at the end of special school time, getting established into a pattern of employment, job opportunities, activities—whatever it may be, depending on the extent of intellectual disability. That is a special time when kids need the support of their families. Once they can get through that little period of time then they deserve the opportunity to be able to have an individual life.

Senator BOYCE—We have talked before about the fact that families often do not plan, because they have a 'what's the point?' attitude. They think: 'Nothing is going to happen until I die or become terribly ill, so what is the point of planning? There is nothing out there for me.' But, once the parent has died, what sustains the safeness and the support? What sustains the plan for the person with a disability? Do you see the board that you are talking about being part of doing that?

Mr Horan—No. Really, I was thinking of it as being a practical board that would make sure that you get the houses and villas built for the government. If you recommended that there should be so many houses—or villas or other accommodation—a year built in each state, you really want that to happen well and you want it to be well managed. With the expertise that is out there, people would not be looking for money to be on those boards; it might be just a modest stipend for their costs. There are plenty of outstanding builders and entrepreneurs, and there would be a good mix on the board, with some representation of the carers, so that you get those places built smartly and efficiently and so that that money can put as many roofs over heads as possible.

I think you raise a good point about the ongoing care and I have probably not thought enough about that. Organisations like Endeavour have been wonderful. I do not know what we would have done in this town without Endeavour. Over the years they have had their financial difficulties and they have overcome them. But, if you go back a few years, Endeavour provided a lot of accommodation, a lot of activity centres, a lot of work opportunities and so forth. If you had taken them out of our community it would have been an absolute disaster. They were the key for this big regional city. And there were a lot of other organisations as well. I used Endeavour as an example because it was their prime, core business.

What you are getting at with the management of the villas or the houses is that you have to have either a government department or an organisation. I would far prefer to see an organisation like Endeavour have the responsibility—it might be that others are picked in other places or even here—and have a charter to manage. It has got to be organisations that specialise in that. The board of builders and other people that I was talking about is not specialised in the care and the needs. I think I would put my trust in an organisation whose core business is providing the care, the support, the workers, the activities, the employment and other things.

What you are really saying is that as people get older they want to know that, when they pass on, their children’s affairs, their daily care, their transport—all those things—can be managed. I think you need a specialist organisation whose core business is that.

Senator MOORE—Mr Horan, in your comments you have been concentrating on people with intellectual disabilities. Is that where your mind has been on this or do you see this as a model that could work for other people as well?

Mr Horan—Yes, I think it could work. I concentrated on that because it was the terms of reference and it is a dire need. I think this could be used as a model for others. I mentioned autism. Over the years people have come in. You admire the care that they have provided for their child, but it has got to a point where it cannot be managed anymore at home, and the other kids are saying to their parents, ‘We cannot hang around here any longer. It is too hard.’ Sometimes there is violence and all the other things that can go with a severe disability of some sort.

I have seen parents have such tragic difficulties when trying to find a placement in some of those very difficult or extreme cases. They can sometimes move from one place to another, depending on the management and depending on the behaviour. It is difficult to get a big boy or a man who can occasionally be violent placed somewhere. You have to ring around. It is really important to find a way for that. I have seen people with those sorts of disabilities at times put in the Baillie Henderson Hospital. It is entirely wrong. It is done in desperation for a period of time until they can find something else. It distresses the parents and the resident.

It may well be that if you had villa style accommodation for some severe disabilities that you would need more intensive carer support, but I still think it is a good model. It might be that in one villa where there are very difficult cases to manage there is one carer per resident and in another villa where there are mild disabilities there is one carer to three residents. I think we have gone past the days of institutions. We are now in a time when wherever possible we give people the opportunity to live their life in an individual way. Sometimes that is not possible because of the extent of their disability and that does mean having a village or a community that is specific to providing safety for them and others around them and upping the care and the opportunities to the max.

Senator MOORE—You know there has been this big philosophical push about not recreating institutions and how you effectively balance the size of the group. I think we spend so much time arguing over that that we sometimes forget the needs of the people. Your comments tended to make that balance between people with real need and how you look at that within a community. We have heard so much evidence in a number of inquiries about people who are very fearful about the re-institution model because of need—and it is desperately because of need. The large Hainsworth kind of model worked really well in the 1950s and 1960s, but we have moved well beyond that. Is there anything you would like to add to that, because I know you have thought very hard about that?

Mr Horan—I think the institutional model was almost like a boarding house. Endeavour have a lot of places around Toowoomba. They even have two-storey buildings with rooms. The principle has been to try to give people, as close to possible, their own house or cottage. In a villa model you can have three or four duplexes, cottages, units or whatever with nice surroundings so it is very pleasant and they can have a little backyard of their own and all of that sort of thing, which goes to making it their own home. You also have a degree of security—and we should not get hung up on the words we use—or safety for them so they do not wander away and get lost. We just keep giving them the maximum potential for life. If they are able to work, there is a little bus that takes them to Endeavour if that is where they are working. If they are able to get part-time work or full-time work in a business, they probably would not even need to be in a villa.

I think institutions are the past. We have moved on to this type of accommodation. It is contemporary, modern and safe and gives them individual freedoms and opportunities to the max within their safe limit. You have to put yourself in the minds of the parents. What would you want if you were their parent? I think any parent would be happy if they felt their child was in a modern place that was safe and knew they had opportunities to go out and they could visit them and bring them home.

Senator MOORE—How we get that balance right is something that has always troubled this committee. I have one more question. I know this is normally a local government issue, but, where we are looking at having any kind of facility or home for people’s needs, there is often community outrage—‘not in my backyard’. I hasten to say that I have never heard of that in Toowoomba, but this is a national inquiry. From your perspective, at a state government level, how do we actually get through that? We have heard about this in a number of places. For all kinds of special needs, not just for people with intellectual disabilities, how do we actually get community engagement in this kind of activity?

Mr Horan—I think it is important to have absolute community engagement if you are going to have a house in a suburb. I mentioned the two that are fresh in my mind—the one at Harristown and the one at Middle Ridge. I think the people at Middle Ridge were, at first, a bit alarmed, but they have all settled in because it is well run. The garden is spot on, and that is important. If you are in a suburb that has beautiful gardens, you have to maintain the residence to that standard.

Senator BOYCE—Especially the lawn.

Mr Horan—Yes. So there has to be adequate money in the budget for the gardening service to come in once a week. That is only fair to the people on either side and behind and over the road. That one has worked well. The carers have had to go and have a chat to the people next door and over the road, but it has been well accepted. It is the same at Harristown. There is a Christmas party at the Harristown one every year. The Catholic Church run the one at Harristown. All the neighbours come to the party. End everybody knows the boys; they have been there for years. So, sometimes it takes time. I think there has to be very careful consideration when placing a group of people in a house in a suburb—that means people with a mild to moderate disability. The other idea, a villa, in many ways overcome that problem; you have adequate space to the boundary fence and so on. I do not mean that in any sort of nasty way; I just mean it is important that the community accepts those with disabilities and takes them into their suburb. If you are establishing a villa local and state government would have to work closely together in talking to all the people. You have to have a meeting in the suburb and invite everyone—at someone’s house, or whatever. You would show them designs and any ideas and ask them whether they could be involved in it. There are things that concern families. You have to tell them there will be 24-hour care and there will not be more noise than what might come from the other houses in the street—they have the odd party, too. You would have to get them to accept that they could be proud to have these people and their families in their midst and that it will enhance their area. When you try to develop a villa, if you make sure that it enhances the area it makes the acceptance a lot better whilst at the same time providing a wonderful facility for the residents.

CHAIR—Thank you very much for evidence; it is much appreciated.

Mr Horan—I thank you very much for coming here and taking the time to hear all the submissions today. I am sure there will be some good ones for you.

Proceedings suspended from 11.19 am to 11.36 am

RAJU, Mrs Catherine Patricia, Manager, Pave the Way, Mamre Association Inc.

WARD, Mr Jeremy, Consultant, Pave the Way, Mamre Association Inc.

CHAIR—Welcome. I understand that information on parliament privilege and protection of witnesses and evidence has been provided to you. We have your submission, number 18, and we have your supplementary submission addressing the new terms of reference. That will be put on the web site as a supplementary submission. Would you like to make opening statements?

Mrs Raju—I will give a brief introduction to Pave the Way and then I will address some of the issues raised in the original paper, and Jeremy will supplement that with some comments about the supplementary paper.

Pave the Way is a small team working within the Mamre Association, a family support organisation in Brisbane. We are a small team that works on a state-wide basis aiming to work with families around clarifying the vision they have for the best possible life for their family member with a disability, explicitly planning to put that in place and then looking at how they can safeguard that plan, that good life, into the future. We do not provide direct service provision in terms of case management or key worker role to families.

Our approach is to assist families in a way of thinking about how they can tackle the question of what will happen in the future when they are not longer there. We do that through a number of strategies, including a workshop program delivering one-day, half-day and small conversation events for families, including some live-in workshops and long weekends, which are held over one weekend and there is another over two weekends separated by a couple of months. We deliver those right throughout Queensland.

We also have an information strategy that provides written information resources for families to assist them in their thinking about their planning—an information strategy that is not a referral process but simply a way of trying to elicit some of the questions families have about planning. What are the issues addressed in these? What are the pros and cons? What is the true information that they need to have before they make a decision? As part of that information strategy we provide legal information and guidance around the issues to do with planning, particularly estate planning, wills and trusts, guardianship and administration. It is not a legal service, as such, but legal information and guidance.

In one way we do work individually with families around their planning, either in informal conversations or more formally through a structured facilitated planning process. We encourage families to invite other people in their network and friendship and family groups to and we facilitate that planning for people. Another way we work directly with families is when they wish to formalise that network of people around them into an ongoing circle of support. Our role in that regard is to assist families in the establishment and maintenance of that circle, not remaining with them in any way but as an ongoing resource to support the circle of information or guidance along the way.

We do that on a state-wide basis in Queensland. We have so far visited over 44 regional areas of Queensland, including Normanton, Mount Isa, Cloncurry, Richmond and along the coastal towns and in the south-east regions. We have a basic website that offers our information and we have a mailing list of over 1,300 families.

When I start I want to say that we are picking up on the first part of the terms of reference; looking at planning options. We are not looking at services, because we do not work in that field. I would like to look at the definition of planning, which we believe is an important one when we talk with families and I believe it is also important in the terms of reference for this inquiry. It is looking at planning as really long-term, whole-of-life, safeguarding planning that is family driven and family based as opposed to what we might call service planning, which is the sort of planning that families are involved in quite often, whether it is in education, the health system or in any services they are involved in. But that is planning around that service and the services delivered by and directed by that service. What we are talking about is planning for a whole life and an ongoing life, and that is often family business. Our role in that is not to direct or control that planning but to assist families to do that planning themselves with other people. Also involved with that planning is that we are not considering this to be crisis intervention in any way, but it is long-term planning that applies succession planning for people of all ages and families.

In that sense we see succession planning, which is the model on which we are funded, as not just an issue for people aging with disability and their carers, although that is the terms of reference. But we think it is important to consider this as something that applies to all ages, as some of the earlier speakers said, so that perhaps we are less likely to have this great crisis of support issues for aging carers in the future. Some of the very interesting work we do is with very young families who are already thinking in terms of how they can envision, plan for and safeguard the good life for their sons and daughters into the future. Although, when we talk about the issues of aging carers, we do find that, even though we are not talking about direct service provision, the way we talk about planning is still highly applicable and very appealing to families of that age because they are still interested in what is the best possible life for their son and daughter and how that can be safeguarded. People may put plans in place thinking that that is the final solution for their son or daughter, because a place has been found, a roof over their head has been found but we all know that circumstances may well change in that regard with a change in services or a change in legislation. So people need to have in place some thinking in their planning that lies beyond or beneath service planning. That is where the work of Pave the Way comes in, which is not to say that the funding and services are not very important. But there is a question about planning that lies beyond that, which is: who are the people involved in knowing my son or daughter and being there to bear them in mind in the future?

Another definition is that our kind of planning lies outside service planning. So, as a planning organisation, while we are at the moment under a family support organisation, Mamre, we are looking at moving to be a more arms-length hosted agency so that boundaries are not blurred between service planning and planning that is family driven. That is a part of our experience and part of what I think has been successful in the work that we have done.

Another thing that we have found has worked over the years that we have been working this way, which is since 2002, is around the concept of readiness. Work with families in this regard should not be seen as a one-off short-term episode of planning. In our experience we find that to have recurrent funding in this way allows us to work with families at the point when they are ready for that kind of planning. It is not an uncommon experience for us to have a family say after they attended a workshop, for example, two years ago: ‘I know that stuff is really important. Now I am ready and now I am here to have that conversation.’

If a planning organisation was there in the short term, why not a little drop of money? That does not allow that developmental kind of thinking to occur for families, or for them to tap in and respond to us in different ways as their circumstances change. It is an ability to respond to different people in their own time, so we cannot use short-term projects. The other thing is that a range of options needs to be available for families: simply people who are able to respond to written information, those who workshop information, those who want a one-on-one conversation or those who like to engage other people in their thinking and planning. We do things in a range of ways. If it were offered as a one-off, I think it would be less successful.

One of the other things we address in our paper is the particular issues of working in Queensland. The size of the state and distances are very big issues in that regard. Pave the Way takes very seriously trying to work regionally. As I said earlier, we visited 44 different regions in Queensland. The cost of that is quite huge, as you would imagine, with some return flights costing $500 to a little place. Sometimes there is only one flight in or out of a town in a day. Recently I was in Bowen for a one-day workshop but had to stay two nights because there was only one flight out of the town and it meant driving et cetera. That needs to be understood and taken seriously if this sort of quality of planning is to be able to be done on a state-wide basis in an ongoing way. We have a website. We were looking at using different technologies for this kind of work with families, acknowledging the remoteness of families, the age of families and where the internet is not the answer to every maiden’s prayer. We take that very seriously. It would be glib to drop to that kind of approach and think that is all you need to do.

In our paper we address the gaps in whole-of-life, long-term safeguarding planning that we have identified. Two of those have been with particular communities in Queensland, with Indigenous families and with people from culturally and linguistically diverse backgrounds. We have had contact with Indigenous families in our travels in Normanton, Richmond, Mount Isa and Cloncurry, but I think we would both say that we do not think we are being particularly successfully that regard. When we have had that opportunity we have worked closely with people who have experience and knowledge in working with those communities of people, but we do not really completely understand what some of the cultural or community issues are that make that more difficult. It is similar with culturally and linguistically diverse communities. We have taken on to translate a number of our basic documents into a range of languages. We have those available on the website. We have also given those to communities, to people who work with those families, but I think we can be much more proactive in that regard. We wonder whether particular people with experience in working with those communities may be better placed to do that kind of planning. We would be happy to work with those people to help them understand the approach that we take to that. It is just a question that we always have.

With regard to planning work, we work with people with a disability who have families around them. We are a family oriented program. That partly comes from the fact that we were sponsored first by Mamre, a family support organisation. The impetus of our planning came from parents beginning this project and asking the question: what will happen when I am no longer there, either as a parent or as a sibling, for the person with a disability? Our focus has been to work particularly with people with intellectual disability who do not have the capacity to make decisions for their own life. The obvious gap is people who do not have supportive families around them. We are increasingly being asked to do this kind of work with people who have lived in institutions or have been remote and isolated from their families for a long time, but we are not in a position to take that up. There are also people with a physical disability who have the capacity for their own planning. Forward planning is not an area of work that we do.

Another potential gap perhaps is people with mental illness. Many families who have a relative with mental illness come to our workshops and talk to us about the work that we do. We certainly believe that the principles of our work apply right across the board, but it is in the implementation of some of the strategies that it becomes difficult. Families are particularly attracted to the notion of networks and circles of support, but the implementation of those, when the individual is resisting or does not acknowledge that there is any particular issue, becomes quite problematical. So it is an area that we do not shy away from but where we consider there are some very particular issues.

Another one that, potentially, might be considered a gap—and this is addressed in the supplementary paper—is when families say ‘we have no-one to talk to’, ‘no-one to do this planning with’ or ‘no-one with the role of doing that long-term thinking and safeguarding’. That is a common response from families. Our response to that would be that this is not necessarily a cast of thousands that we are talking about. However, the approach of having a conversation with one other person, even if that is an explicit conversation, with siblings or with other family members is better than not having those conversations or not ever speaking about those understandings but making presumptions. That is one of the interesting pieces of work that I think we have done with families. So, while it may be considered that there is a gap for people who do not have people around them, that is not necessarily always the case.

Another gap we have identified has come from requests to us to do this work in other states of Australia, because there does not seem to be another funded organisation that works in that big-picture, whole-of-life, long-term planning area. There is a small organisation in Victoria and another in Western Australia that are similar, but we are frequently asked to go, and have gone, to New South Wales, Victoria, South Australia and Tasmania to present our workshops and information. We are not funded to do that, of course, and can only do it when we have the capacity or when they are able and prepared to pay us to do that. We would be interested in talking and happy to talk to people in other states if we had the funding and resources to do so. I will pass over to Jeremy for some of the issues raised in the supplementary paper.

Mr Ward—Thank you. There are just three points that I wanted to speak very briefly about. The first is the concept of individualised funding as a way of helping families see how they might better safeguard the future of their family member with a disability as well as safeguard their vision and dreams for the future. We would describe individualised funding as funding that is assigned to the specific individual which is in the control of that individual or their family and which can be transferred between services at the direction of the individual or family. Increasingly, some families are interested in this option because it allows them more flexibility and more control. They can be involved in choosing staff that are appropriate to meet the needs of their family member. They can be involved in training and supporting those staff, monitoring them and so on.

On the family support side of Mamre, which works in the Brisbane area only, we are supporting approximately 200 families, and around 165 to 170 of those families are now choosing to manage their own funds. That means that funds are transferred to them on a monthly basis and there is an agreed support arrangement, a family support plan, which is a different sort of plan from what Catherine was talking about. It is a plan negotiated between Mamre, the service and the family. That can include planning issues beyond the actual expenditure of funds, but it can include that. This can be very accountable: families have to account for the funds on a monthly basis. They are supported; they are given information and advice about how to deal with employment issues, tax issues, ABNs and so on. Mamre runs workshops for families to assist them to take those things on. Some of the families, incidentally, who are engaged in this are receiving considerable amounts of funding—for example, $100,000 a year or over—but most would be receiving much less than that.

We believe that this is a way that families can look at the sort of future that they want for their sons and daughters or other family members and make suitable arrangements to implement that, and then use those funds flexibly to meet the needs of the individual and also comply with any funding guidelines, rather than having to fit into a box because a particular service says, ‘You can either take this or not.’

The next point I want to mention briefly is the idea of taxation relief and future planning. In our submission to the Productivity Commission we made the point that if families were allowed a tax deduction for expenditure incurred in supporting their family member, this would make a huge difference to those families. It would also be a way, I suppose, in the framework of the Productivity Commission’s brief to look at the funding of support for people as a tax relief sort of notion. Also, close friends and relatives, so long as their use of the money is to support the individual, could be allowed a similar tax deduction.

As you will appreciate, the costs of disability for some people certainly can be massive. The cost of modifying a bathroom could be between $10,000 and $20,000. The cost of making a van wheelchair accessible could be $28,000 to $30,000. In Queensland there is absolutely no subsidy for any of that. There is a subsidy in some other states for some of that, certainly for the modified vehicle. The cost of providing one hour of paid support per week for a year would be, on our calculations, in the vicinity of $2,000—$1,800 to, say, $2,200. So if a family wanted to pay for an additional 10 hours of support a week for a year—that is less than two hours a day—they could be facing a bill in the vicinity of $20,000 to $22,000. If those costs were tax deductible it would make it much more doable for many families and would take the pressure off government in other ways.

Finally, I want to make a very brief point about the cost of providing a service like Pave the Way. Again these are very, very rough figures and we would undoubtedly stand to be corrected by people in some of the other states. We are just basing this on what it costs in Queensland to do what Pave the Way now does, which is approximately $600,000 a year. Assuming that states of equivalent size and issues of distance would receive a similar amount and other smaller states a lesser amount, we think it would be in the vicinity of $3.5 million across Australia. That would not take into account perhaps specific projects that Catherine mentioned relating to planning options for people in those specific areas of cultural identity and Aboriginal and Torres Strait Islander communities. Those are just very, very rough figures and we would not necessarily want to be held to them strictly, but they just give you an idea of what we think the ballpark figure may be. I hear some of the other figures bandied around in the disability sector. If there was a state-wide or territory-wide planning agency similar to ours, necessarily targeting the particular issues in those communities—we are not saying you do it just the way we do it; everyone needs to do it their own way and it needs to be grassroots driven from the particular states and regions—then being able to spend that sort of money across Australia, not overnight but in the longer term, would make a huge difference to families across Australia. Thank you.

Senator BOYCE—Mr Ward, the $3½ million a year you were talking about: is that to provide education about whole-of-life planning and to support some people’s planning?

Mr Ward—It would be to do something similar to what we are doing here in Queensland, which is running workshops, providing information, running a website, providing one-on-one consultations with families, facilitating families’ planning sessions, assisting with the development of support circles and networks—

Senator BOYCE—For, I think you mentioned, 200 families?

Mr Ward—No, we—

Senator BOYCE—It would cover more than that?

Mr Ward—It is hard to say. Catherine may want to answer this but, in terms of the demand on Pave the Way, if we went out and promoted Pave the Way by advertising in every local newspaper we would be swamped.

Senator BOYCE—That was where I was getting to.

Mr Ward—We now have 1,300 families on our mailing list—we send a newsletter every quarter, we send out other information and we have been tracking the special disability trust issue, for example, and providing families with up-to-date information. We are also looking at piloting a new approach next year where one of us will arrange to visit and have conversations with families in remote communities. That is what we call the road trip approach. If that works well in south-west Queensland, we will look at other remote parts of the state. All of that will be included in those figures. We could use a lot more money, but we are being very reasonable here.

Mrs Raju—You said 200 families, but we do not have families. It is not like the family support side of Mamre where there are families attached to that service. We do not have families. We might have someone who reads a newsletter four times a year and that is it. We might have someone who comes to a workshop and does not see us again for three years and then engages in some more intense conversation. We do not do the follow-on implementation of the plan. I meant to make that clear earlier. There is certainly a need for that, but that is not a service that we deliver.

Senator BOYCE—You mentioned organisations in Western Australia and Victoria. I am assuming you mean PIN in WA. What is the Victorian organisation?

Mr Ward—Personalised Lifestyle Assistance.

Mrs Raju—It is a very small organisation that works with a set number of families with extremely limited funding. Similar I suppose is the approach they take to planning in terms of long-term safeguarding planning and assisting families with networks and circles of support.

Senator BOYCE—You have made that very strong distinction between service planning and whole of life planning. What we have come across over and over again in evidence is that parents and carers often just do not bother planning because they do not see the point of doing that. They can do the plan, but if there are no services to plan the plan around then what is the point? What is your response to that?

Mrs Raju—We suggest to families who may have come to us originally with that thought that, whether there is a hard service at the end or not, long-term planning applies anyway because it is talking about imagining the life that could be there and safeguarding that person in the long-term. If families wait for a service to happen, nothing will happen. For many families there will not be a service and there will not be any funding, but life still moves on. Sometimes people understand that and believe that they are going to have to think about what is going to happen in the future, and that sort of thinking applies. If a service comes along then that is fine but if a service does not come along then they still need to have their legal affairs in place, they still need to have some other people involved in their child’s life, they still need to share their vision with those people and they still need to be on board to bear them in mind whatever the service might be or whether there is one or not. That is partly the answer.

Mr Ward—I would also be asking families who have that view: how do you know whether there is anything out there unless you have done some planning to work out what it is that you want? It is about planning for what they want and what their family member wants and then looking to see how those goals can be met. Some of them will be met through traditional disability services if they exist, but even if they do exist you need to identify which are the right services.

We heard about the model put up by a previous witness today. For many families that would not be what they want because they have done some planning and realised that what they want is their family member to live a life very similar to their other kids. That congregate model would not necessarily suit them. It is about doing the planning, working out what it is that people want—we call that the vision question—and then looking for how those plans can be implemented.

Mrs Raju—One thing that families find when they begin that planning is that there are small things that can begin to happen without a service.

Senator BOYCE—Are you able to give us an example of what you are talking about there?

Mrs Raju—One of the things that we look at in planning is what the aspects of life are that we plan for. In that sense, we are talking not just about a house—a roof over your head—safety and health but also about things like interest, hobbies, passions, engagement with other people, relationships and friends. Some of those things can happen without a service being provided.

CHAIR—Does it not become something that you can advocate for as well?

Mr Ward—Exactly.

CHAIR—This is what our vision is; this is what we are going to go out to achieve.

Mr Ward—That is right. That is what you can use when you go to talk to a service. You might say, ‘You’re the only service in this region that is providing something in the area of accommodation but what you are providing does not suit us. This is what we want. We want to talk to you not about what you are now offering but about whether you can be flexible enough to support our family member in the way they and we would like them to live.’ Some families will respond to that. This is where individualised funding helps, if the funding is attached to the individual rather than to the service. I am not saying that services do not need their own funding but, if the funding is attached to an individual, they can go to that service and negotiate. It may be: ‘We just want you to administer the funds and cover all the legal and administration issues. Yes, you are entitled to have a fee for that. But we will look after all the other direct service provision issues.’

There are lots of examples in the financial area. I was in Atherton on Friday and a young parent with three children, all with disabilities and all under 18, said that she and her husband had bought as much term life insurance as they could afford, because they knew that, if anything happened to them, these kids, as they are now, would require a lot of paid support. That has nothing to do with services; that is about sitting down and thinking about what is going to happen if that bus comes along tomorrow.

A family may have as part of their goal to develop relationships. As you would appreciate, this is one of the biggest issues for many young people with disabilities, particularly. Their goal may be to make a concentrated effort to develop a close group of friends or people that the young person can associate with, say, in the next 12 months. They may, for example, in a supermarket meet up with an old school friend or a young teacher’s aide that used to get on very well with the person. They meet and they say, ‘It’s really good to see you; haven’t seen you for a couple of years. We must catch up for coffee.’ Instead of just leaving it at that, because the family has in their mind, ‘This is an opportunity; our goal is to develop relationships,’ they will say, ‘Can we have your phone number?’ or ‘How about next week?’ They actually take the initiative. Nothing may come of it, but that is what we mean when we talk about planning as being a way of thinking—this constant way of thinking. How can we use a particular opportunity or choose between A, B and C opportunities unless we know where we are going, unless we have a vision, unless we have a plan?

Mrs Raju—Families who have looked at the notion of health or sport, may wait for a funded disability specific recreation service or sport service, or it may be that, in a planning session—and this has actually happened with a family—another young person involved in that planning goes to a gym and suggests that the young person may accompany them, and all that is required is a gym membership, which could be paid out of a disability support pension or whatever. That then meets a whole lot of needs that have not required a funded service to be in place. So it is in a way a switch in the way of thinking.

Senator BOYCE—Yesterday we had evidence from Family Advocacy in New South Wales—a group that you will both know—about the fact that there is a generation of carers who have in some ways been groomed by the current system to accept what they are offered and not to dream—to passively take what they are given. Both in terms of how this group would develop the sort of thinking that you are talking about and also how this group could, once they have a plan, go about actually implementing would also require energy and putting yourself out there. Could you talk a bit about that, please?

Mrs Raju—Before I go on to that one, I would like to give you an interesting observation of some people who have had that thinking. This was a family who had been on one of our recent live-in workshops. They arrived thinking, ‘I probably don’t need to be here now because I’ve just been offered a place for my son in a shared house.’ They thought that that was the end. It was interesting that, by the end of the live-in workshop weekend, they had begun to see that that was not in fact the end—it was the beginning and that there was a whole lot of other planning that they needed to do about the quality of his life and the long-term safeguarding of that. So there is potential for change from the orientation of people who think that services are the answer to seeing this other kind of thinking and planning lies below that really.

In terms of energy and assistance in implementing that, I think that can be a gap in this way of thinking for people. There will be some people who need a bit more instrumental assistance to implement their plan. If people have some involvement with a family support service, sometimes a key worker can assist in helping them implement some steps of the plan which they have been unable to do because they have been in a very passive mode, if you like.

Mr Ward—It is really about trying to get people to think that there is another way. We use lots of examples and stories and we might get other families to talk to a particular family. But there has to be some sort of triggering of a thought that maybe there is a different way of doing something here. As Catherine said, people will come along to our workshops or they will read our information and they will think about it. Some of them will even say that it has been absolutely challenging and, to some extent, life changing in the way they think, but they will not necessarily feel that they have the energy to do anything for some time.

The other thing that we have observed elderly parents being supported to grapple with these issues is through siblings of the person with the disability. There have been a number of situations where brothers and sisters, siblings, have come to our workshops and brought along their elderly parents and then assisted them. There was one situation where a sibling did that and she then instigated with a little bit of support from us—she did not need very much at all—the setting up of a support circle around her sister. We later talked to the parents and they said things like, ‘We can now sleep because we know there are other people who are going to be there for our daughter.’

There are some elderly folk who really do bite the bullet, so to speak, but they are usually people who, unfortunately, have had a bad experience. If you had talked to them 10 years ago they would have said, ‘We’re fine; everything is fine; the service is fine. We’re retiring and getting on with our lives and we’re happy that everything is ok for our son,’ and then something terrible happens, such as an incident of abuse. I know of at least two people who have had to bring their family member home and start all over again. They certainly responded to the sort of approach we are taking.

Senator MOORE—In the interests of time, I will only ask one question. It is to do with funding. My understanding from your submission is that you are funded from DSQ for a specific purpose and it is for the current year. Do you have to go up for that again?

Mrs Raju—No.

Senator MOORE—Are the services that you offer, the workshops and so on, free for individuals?

Mrs Raju—They are free for families. The only contribution is a very minimal one towards live-in workshops.

Senator MOORE—So the DSQ funding covers that service?

Mrs Raju—Yes. We could always do with more assistance to do some of the regional work, though, of course.

Senator MOORE—I think your submission covers that as well.

CHAIR—As you can see, there is a deep interest in this particular issue. It goes to the heart of the terms of reference. Thank you very much for your evidence, your submission and your supplementary submission. Obviously, we have not had a chance to read the supplementary submission. That is absolutely fine, but there may be a few questions on notice that we may want to follow up once we have had a chance to read it. Thank you.

[12.16 pm]

McKENZIE, Mrs Fay, Private capacity

McKENZIE, Mr Peter William, Private capacity

CHAIR—You have been sitting listening to the pack drill, so I will quickly go through the introductory remarks and then we will get started. Welcome. I understand information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. Do you have anything to add about the capacity in which you appear?

Mrs McKenzie—We are here as elderly parents.

CHAIR—We have your submission. Thank you very much. It is No. 77. I would like to invite you to make an opening statement and then we will ask you some questions.

Mrs McKenzie—Thank you very much. We have been researching accommodation avenues, Peter and I, for quite a long time. In 1993 we placed our son in an Endeavour Foundation residential home, where he was expected to purchase and prepare his own food. Unfortunately, he did not have the capability to do that, so we withdrew him from the service. We placed our son in a home, privately funded. Unfortunately, although he enjoyed the company of the other members and appeared to be fed adequately, there was no night supervision. As we found out later, he would stay up and watch movies through the night. He was regular in waking up for work the next morning, but the combination of this hectic life caused him to lose weight. When he, at 159 centimetres, dropped weight to 46 kilograms we withdrew him from the home. We tried leaving our son to rent a house with his sister. Unfortunately, her health broke down and together they could not cope.

We looked at other avenues in Toowoomba. We had our son on the Endeavour Foundation accommodation list, but that was closed, except for disabled people with government packages. Our son was very low on the list and would not have been eligible for a package. We thought about leaving our home to Disability Services Queensland but had observed poor results, with houses becoming run-down and clients not being well looked after at that time. That was in 1995. We felt the accountability of staff was not satisfactory.

We had the option of leaving our son on the doorstep of Disability Services Queensland. Again, there was the option of him being placed with other people left on the street. As he is very vulnerable to doing things to please others, we felt this was an unsafe situation. Another option was to place him in a retirement village when he was old enough. In another 10 years we will be 84. We have a disabled friend living in a retirement home and it is proving to be very lonely for her as the other retirees do not really communicate with her and she has little community access.

Breakaway, a service group in Toowoomba with respite facilities, have been very helpful. They have funding for the older carers program—which is us—and have provided respite for two separate weeks a year for the last three years.

Then we came across the Anden. The purchase of the Anden, a B&B in North Street, Toowoomba, in 2009, with funding from the federal government, delivered by the state government and then purchased by the Department of Communities Queensland, has proved to be a wonderful opportunity for our son and five other residents with a disability to have a safe, secure, permanent home. It means an awful lot. This has been a wonderful opportunity for our family. Our son was in a grey area—he is not a person with a high-level disability able to receive a package and not a person with a low-level disability unable to manage on his own even with daily carers to help.

I have decided to give you a bit of a description of The Anden. I know I was not supposed to talk a lot about services at the Anden, but I thought it was important that people knew just how we were able to receive accommodation at the Anden—The Older Carers Program through Breakaway; HACC, introduced by Centrelink; Karalee Baille Henderson, KBH workshop; Carers Queensland for legal advice; the Public Trustee for guardianship information; TASC for advocate services; Family Planning Queensland for parents and residents; and tenpin bowling for slow learners. After leaving the farm and moving to town, our son became very unsettled. The Older Carers Program proved to be an excellent transition period for living at the Anden. He had one week’s respite with other disabled people twice a year for three years. Centrelink advises that our son was eligible for four hours of one-on-one care once a week. This has been very beneficial for his feeling of independence. He was able to join a Breakaway social group for five hours per week. This is a very happy group who travel into the community to do different activities. It was fortunate that he was accepted by KBH, a supported workplace, for three days employment. He loves his job and loves being paid. This is good for his self-esteem. Tenpin bowling once a week is a favourite pastime. These occupations proved to be excellent as it meant he was occupied through the five work days and Saturday morning. Our son returns home from bowling for a Saturday sleepover and returns Sunday. We feel that this has helped with our son's transition from family to the Anden, as he still feels part of the family but he enjoys going back to his Anden friends.

The Anden was purchased by the Department of Communities Queensland in 2000 with central funding. It is a large Queenslander type home that has been extended to become bed and breakfast accommodation. It contains six large bedrooms with ensuites, staff bedroom, toilet and bathroom, large kitchen, separate dining room, pool room, laundry, office and a large living room. The house is situated in an easily maintained garden. It has a large garage with excellent parking and it fits comfortably with neighbouring houses. I was interested before when somebody talked about not fitting into the neighbourhood. The man next door comes over and picks the mulberries just the same as he always used to, so we feel as though we have fitted in reasonably well in the neighbourhood.

The Queensland Community Housing Coalition, with the YWCA, maintains the property. Installation of water sprinklers, the updating of some areas of the Anden to make it disability safe and connecting phones to all rooms in case of emergencies have been completed. Residents are charged $260 per fortnight in rent by the YWCA. Breakaway is the service provider for the Anden. We have been very fortunate at the Anden to have wonderful staff. Parents are included in the initial selection of the staff. The staff chosen are well educated, experienced in welfare work and young enough to manage the complexities of establishing a new home.

Staff are rostered to care for residents seven days a week, overnight from 3 pm till 6 am. Two morning staff work from 6 am till 9 am, which includes helping with breakfasts and taking the residents to their workplaces. One afternoon staff member working from 3 pm to 9 pm collects residents from their workplaces and assists the overnight staff. There is 24-hour care on weekends and holidays. The coordinator is on call through the day while residents are at work. The kitchen staff begin at 4 pm and finish their shift at 7 pm. All meals are planned in consultation with the local dietitian. Professional cleaners clean the entire house weekly. Staff help residents to change their bed and bathroom linen weekly. Breakaway charges residents $140 for food and $50 transport per fortnight, which we feel is very reasonable.

The residents had a beachside holiday for a week when community housing completed the improvements. This proved to be a happy occasion and we are hoping that that can happen once a year. Anden residents always look suitably dressed. Residents do their own laundry with carer supervision and fold and pack clothes away from the outside clothesline when dry. Staff complete the necessary ironing. Once a week, each resident has a personal staff member to help check their clothing and to list necessary replacements. The resident shops for those necessary items with their five-hourly, once a week, one-on-one carer. Residents are encouraged to have a few set jobs in the house, such as setting the table for the evening meal, clearing the dishes to the sink, watering the roses and picking the mulberries. Residents cut to their own lunches for work under supervision and, with their carer, often take walks to a local shop for small kitchen supplies such as milk or bread. That is more a means of getting them out of the house and doing a job rather than because there has been a slip-up in the ordering.

An individual exercise program using gym equipment is being set in practice. Residents have established social activities at the weekends. These include: tenpin bowling, cricket, horse riding, a theatre group and a disco dance Down syndrome group once a month. Residents play pool for recreation and have Friday night in-house movies. Some residents return to their parental home for overnight stays on the weekend. All residents have a daytime activity to attend through the week. At this stage residents have returned home when minor illnesses have occurred. Carer support can be arranged for minor illnesses at The Anden when parents may not be able to care for their family member. Residents have organised, with carer help, a welcome party to The Anden for parents and friends.

Regarding the parents group, initially parents were meeting with the coordinator. Presently, these meetings are held monthly. Parental involvement and Breakaway's sound work practices have ensured the wellbeing of the residents. Parents worked with Breakaway for the successful transition of residents from home to The Anden and together with the staff, the parents are looking forward to working towards resolving challenges ahead.

Challenges ahead include, firstly, what I will call 'recommendations for government developments'. We feel the introduction of a microboard is quite important as the development of an advocate to support the resident. This would continue the accountability of the staff service when parents no longer have the capability. At the moment, the parents are able to walk into The Anden at any time of the day or evening, or whenever, and just see what is going on. Over time they have been able to give their opinion on whether something is a good idea and that has been a wonderful support. Using Breakaway's service provider staff training model, a course could be established to provide a professional career path for support workers. If this is going to be used Australia wide—or however you want it to use it—I think it sets up the necessary professional career path for people. They are support care workers, really, because they are taking the place of the parents.

This may help to overcome some of the difficult legislative processes occurring in the welfare sector where rules to protect support workers may take precedence over the care of the residents. Some examples where this may make supervision of intellectually disabled people more easily managed are in clear directions of government regulations regarding policies for a mixed gender accommodation. We have very good human relations and sexuality guidelines from Breakaway which state:

> Human relations … are the interaction of personal, social and sexual development which allows people to relate positively both to themselves and to others …

But it is not specific and we do not know whether or not in some places you can have married people. What is the answer if some people get to like each other, what happens to them?

To show more flexibility the government may review the administration of medicines. Doctors do not like writing scripts for over-the-counter medicines. We have had a couple of cases of that where one person was not allowed to take vitamin C and the doctor refused to write the script. Another one had an eye problem where the doctors said, 'You can get that over the counter,' but they were not given a script because it was not on a doctor's referral. Simplification of bookwork could overcome the problem of staff on arrival being required to read the report written by the previous staff member of in-house issues. The staff member finishing their shift then has to make a new report for the activities of the day before leaving. We feel this could be simplified as it limits staff time spent with residents. When you have six residents and you have to write something about every one of them it takes time.

As the group of residents at The Anden are getting to know each other a relationship could develop. Breakaway had a human relationship and sexuality policy that is based on respect for others' rights. The mixed gender household is very positive with both staff and parents working together to make this policy work. Anden has approached Family Planning Queensland to aid with educating the staff and residents by introducing and trialling strategies around human rights. In the future accommodation could be offered as one sex only or equal sex for a home of six people.

We recommend that people with a disability could be offered the transitional pathway to secure accommodation at a younger age to overcome some of the separation from parent problems occurring in older age when both residents and parents have become interdependent of each other. It is a very stressful time for both residents and parents. We would recommend that the transition from regular occasional respite to permanent accommodation has been very successful. That means that some people come into the home, they stay there for two or three days, go home for a week and then come back. That goes on for a couple of months and after that they are quite settled and happy. The continuing transition from their parental home to their new permanent accommodation is important.

I have just added here advertising accommodation and availability through Centrelink or a registered agency to all carers would be beneficial to carers not in contact with a support service. Improved communication between Centrelink and the Department of Communities would be advantageous in regard to information regarding new government initiatives and services available. From that we feel that this pilot program developed and funded by the government and run by the government is a successful attempt at providing permanent accommodation for people with a disability.

Senator BOYCE—Thank you very much, Mr and Mrs McKenzie, for coming along and thank you for that really thoughtful submission. I have two questions. You have talked about an enormous project in pulling all this together, getting DSQ to fund it et cetera. Where did the impetus come from and what sustained you in that project?

Mrs McKenzie—I was a member of TIDSA. We did not have very much success with the state government when we applied for Bridge Street accommodation, where there was a retirement home. TIDSA went to Mr Pitt in the state government and suggested that we buy the Bridge Street complex, and he said, 'No, it is not on the books because it is too institutionalised.' After that we did not quite know where to go. It was through the year and we thought, 'Well, we have not had a lot of success with the state government—perhaps we will try the federal government.' So we did. We wrote letters to Mr Ian Macfarlane. He suggested that we write to Mr Mal Brough and to Mr Howard. Sure enough, within three to four weeks, Mr Howard announced, in July, that he was going to give $90 million for intellectual disability accommodation.

Senator BOYCE—That was not a dorothy dixer, by the way!

Mrs McKenzie—After that, we had to go to the bureaucratic stage of the federal government, when it went through FaHCSIA, and they decided to do it Australia-wide, so they had to go through all the cities—and they missed out Toowoomba. So we had to write more letters—

Senator BOYCE—So you had advocated for all this funding that other people got—is that what you are saying?

Mrs McKenzie—We had to write more submissions. I think there were three that went down. They actually came to Toowoomba and it was very successful. We were very pleased with what was happening. Then Mr Rudd came into government in the November. He decided that he did not really want to go on with accommodation but he would give the money to the states. So we thought, 'Right, the money is going to the states.' So we wrote letters. We would have had about 30 letters that we all wrote after Mr Rudd got in. It was in about December. We wrote all these letters—and I am just so pleased that there are so many good letter writers in Toowoomba. When they came back from their holidays they were astounded. They said there were 30 letters sitting on the bench and they were all from Toowoomba, all asking for accommodation. When they decided that the money had to be distributed they gave a million dollars to Toowoomba. With that million dollars, DSQ were very nervous because they had never purchased anything in the past. They had always sold things but they had not purchased anything. It took them quite a while—it took a year—for them to decide, and they chose The Anden, which was a B & B in North Street. Then it had to go through the process of being developed and organised. Because we were part of the older carers program and Breakaway were given the job as service provider and our boy was on the older carers program, we were able to apply for a position. We have been very thrilled with the whole set-up.

Senator BOYCE—One of the points that has come out with whole-of-life planning is what happens when, in your case, 'we' can no longer care or are no longer there. What do you see as being the things that will sustain your plan—your hopes about a good quality of life for your son?

Mrs McKenzie—I am hoping that this microboard might be able to be introduced. I was just hoping that one of the family could perhaps do it. They could have a meeting once a month and could get to know the person. It does not have to be a member of the family—just somebody who takes a personal interest in that person. If they have a meeting once a month they will be able to discuss how they are going, if their health is good, if they are being looked after socially or whatever. I thought that microboard sounded like a good idea for when we get too tired or too old.

Senator BOYCE—Would you see a microboard for all the residents of Anden or each one having their own?

Mrs McKenzie—Each person has their own advocate. That group forms the board.

CHAIR—Of Anden?

Mrs McKenzie—Yes. There are six people in Anden, so they will have six advocates who will be able to carry on the job that we have been trying to help get off the ground.

Senator BOYCE—In your submission you raised transitional planning. There is the idea that ageing carers can become co-dependent with the person with a disability and be frightened to let go.

Mrs McKenzie—A lot of people would not let their children go because they are so used to it. In our case, Peter has lost his foot, but our little fellow is very good at running around. He would do all the messages, put out the rubbish bin, go shopping for the newspaper and do all those little things. People get very dependent on their person. I think would be great if it could be done 20 years younger.

Senator BOYCE—You talked about retiring off a farm. I guess that opportunity just was not there for you.

Mrs McKenzie—No.

Senator BOYCE—I mentioned this earlier: a lot of the policies around at the moment seem to assume that parents will care until they cannot anymore. Do you have any thoughts about how we go about changing that? What do you think should happen there?

Mr McKenzie—Fay has been with TIDSA and Anden since I was on the farm. I just carried on with the farm work and let Fay go ahead. We were just so happy that Scott got a position in Anden. The transition could have been a bit earlier. We would have liked it to have been earlier. We tried and it did not work. To me, the main problem is funding. If the government, any government, could defer or move some of the foreign aid money to local communities, that money would help us and other people make their transition a bit earlier.

Mrs McKenzie—So that we could have houses everywhere.

Mr McKenzie—It just seems to be an ongoing thing that, while the carers are there, they will look after them. It is a worry that, as we get older, we have to fight for it. It is just a pity that there is so much money going to overseas aid. Perhaps some of it could be referred back to this sort of situation throughout Australia. People who do not have a disability do not understand the stress, not only for the parents but for the children and the siblings. If it were done a little bit earlier, that would be great.

Senator MOORE—Where was the farm, Mr McKenzie?

Mr McKenzie—Just out of Toowoomba. Scottie was a great help on the farm. He learnt to ride a motorbike, or a quad bike, and he could drive a car in first gear, as long as he did not go too fast!

Mrs McKenzie—But he cannot do up his shoe laces and he cannot add up money.

Mr McKenzie—We sold hay. I would be down the paddock and someone would come in for hay, so Scott would help him and I would give him the invoice and Scott would go back. He was so thrilled to be able to help. It was very sad when I broke down with health and we had to leave the farm. He was getting impossible to live with, until Anden came along. It was a great help to us.

Mrs McKenzie—KBH has been a great help to do.

Mr McKenzie—He works at KBH and gets $2 an hour, but I would have paid them $10 an hour to employ him. It is not about the money; it is about the occupation, and he is thrilled to bits to get his little pay cheque every Friday.

Senator MOORE—So where does Scott consider to be home now?

Mr McKenzie—The Anden, I think.

Mrs McKenzie—Why does he think it is the Anden?

Mr McKenzie—When he comes home of a weekend he gets pretty miserable.

Mrs McKenzie—And he sleeps.

Mr McKenzie—But he cheers up as soon as he goes back.

Senator MOORE—From your perspective, in your future planning do you believe the Anden will be Scott's home?

Mrs McKenzie—Hopefully.

Senator MOORE—And that is where he believes it should be.

Mr McKenzie—We are very fortunate that the Anden has accepted Scott. If he was not there, I am sure the daughters would help look after him, but we do not want to burden them after they have reared their own families.

Senator MOORE—Are the people at the Anden all young?

Mrs McKenzie—No. They are aged 51, 47, 40 and three of them are 33.

Senator MOORE—They are middle aged. At this stage they are not are looking at their own aged care; they are all active. So what we have is a working solution for this period of life.

Mrs McKenzie—Yes. We do not know what will happen later on with the different services, but I do know that KBH had an 80-year-old man working for them who died last year.

Senator MOORE—He died on the job! Senator Boyce obviously knows the set-up, but I have just heard about it today. We will ask more questions directly of Anden off the record. We are looking at the cost. As you have pointed out, at the moment it is very good value. But I am looking at the costs beyond someone who is on a disability pension. The whole focus of the Anden process is based on people being able to afford to have their services.

Mrs McKenzie—Yes.

Senator MOORE—We will follow up with them in terms of other things as well, but I just wanted to get that clear.

Mrs McKenzie—We have had a wonderful success was Carers Queensland for legal advice. The Public Trustee explained guardianship and everything to us but they have given us the choice of being our own guardians. Peter is Scott’s financial guardian and I am his social guardian.

Senator MOORE—From the way you explain the circumstances, it seems that you are able to get good support from a whole range of organisations along the way. That has not always been the experience of people who have spoken to us in the past. In terms of the list, it was a really strong indication of how effectively this community operates when people have strong community support. But that is not always the case.

Mrs McKenzie—That is right, particularly with Breakaway.

Senator MOORE—We have someone here from Breakaway who we hope to talk to this afternoon. I used to work for the Department of Social Security. You said Centrelink gave you good, effective communication.

Mrs McKenzie—Yes, they did.

Senator MOORE—It is important that that link is maintained as well.

Mrs McKenzie—Yes, I thought so too. A lot of people said they had not had any contact with Centrelink, but when we came in from the farm we had to explain where we were and advise of our change of address. We went up to Centrelink and got our things in order, and that is when they told us.

Senator MOORE—That referral—just giving people the details of where they can go to talk to people—is critical. I am not always convinced that the information sharing is as effective as it should be, but in your case it was. Thank you for sharing that with us.

Mrs McKenzie—Thank you very much.

Mr McKenzie—Thank you very much.

Proceedings suspended from 12.48 pm to 1.33 pm

LANIGAN, Mr Anthony John, President, Toowoomba Intellectual Disability Support Association Inc.

CHAIR—Welcome, Mr Lanigan. I know you have appeared before and you know the ropes but I still have to go through it. I understand that information on parliamentary privilege and protection of witnesses in evidence has been provided to you. We have your submission, which we have numbered nine. I invite you to make an opening statement and then we will ask you some questions.

Mr Lanigan—Thank you. If I may, I would first like to express our sincere appreciation of the committee for choosing to sit and hear public opinion in Toowoomba. Through the chair, I would like to acknowledge everybody who has travelled, some of them since four o'clock this morning from Chinchilla, to form this audience and be part of the public hearing.

Every informed commentator, from the then Prime Minister Rudd down, has recognised that the Australian disability sector is broken and beyond repair. A brand new start is urgently required. Many planning tools are already in place. For example, we have a definition of what constitutes a permanent, severe or profound disability. We can quantify the various forms of disability. Here I would point out that the number of Australians living with an intellectual disability is almost threefold that of the nearest other—that is physical. Gathering and collating this data is not rocket science, yet such figures as are available on the Australian Bureau of Statistics database are seven years out of date. Question the ABS on this and the stock answer is, 'There is no room for such questions on the national census form.' So what priority is afforded the disability sector?

Armed with the magnitude of the unmet need for supported accommodation we then set about purpose-designing the most affordable and sustainable models for such accommodation. TIDSA's formal submission laid out in some detail, and I hope you are familiar with this, a proposal for a small, pilot development in this region. Lessons learned through such a development could be applied to similar solutions across regional Australia. Finally on this subject, I submit that the Commonwealth should assume full responsibility for the standardisation, operation and funding of disability supported accommodations throughout Australia as it does for the aged-care sector.

I note the explanatory notes to the inquiry's terms of reference and those of the Productivity Commission. I do submit that many aspects are inextricably linked. This is especially so with regard to widely held serious concerns about the standard of service delivery in disability supported accommodations. There is a raft of recorded evidence indicating that with few exceptions the disability support industry operates primarily for the convenience of support staff, rather than the service recipient. This is our greatest fear, that loved ones without the cognitive reasoning or communication skills to understand why, let alone question why, are wide open to abuse of whatever nature. Self-regulation by service providers just does not work and is akin to the fox guarding a chicken coop. Compliant behaviour is the required norm, complaints are quickly silenced and events are denied and are simply swept under the in-house carpet. We must have an independent spot-check system which can allay, at least in part, our fears.

The current community visitor, or CV, program in Queensland has 912 visitable sites to be serviced by a mere 29 casual part-time community visitors. Those numbers speak for themselves. I know this subject was addressed two days ago when you were in Victoria. It has been my long-held belief that support workers in the disability and aged-care sectors should be selected, trained, certified and properly remunerated, thus gaining the same respect and status as, for example, the nursing profession. Dependant on the findings of this committee and those of the Productivity Commission in relation to the standard of care prevalent in these sectors, I submit that this be the subject of a future Senate inquiry. I also submit that federal responsibility for disability and carers be elevated to a full ministerial portfolio.

One week and a half ago, I went down to the Endeavour Foundation Council in Brisbane specifically for the purpose of having a brief private meeting with Senator McLucas, the Parliamentary Secretary for Disabilities and Carers, who was able to tell me in her opening remarks there are now something like 790,000 Australians living with a disability. If that does not warrant a full ministerial portfolio and a seat in cabinet what does? She did assure me that Minister Macklin, whom she meets weekly on a Monday, is well aware of the problems and we are well looked after in that regard. I subscribe to the FaHCSIA website, I read every media release from Minister Macklin and I know well over 95 per cent of her media releases relate to Indigenous affairs. What priority for disability?

Finally, I wish to address the problem of meaningful access to governments, in particular state governments. Over the past six and a half years, TIDSA has met with three successive ministers holding the disability portfolio. Despite having provided the usual A4 1½-page executive summary to the department for the particular minister’s attention, not one reached his or her in-tray prior to a meeting. On the last occasion at a regional cabinet meeting when I questioned this the director-general of the day left the table to attend to business elsewhere and that was the last I saw of her. An ivory tower culture appears to abound amongst the upper echelons of our bureaucrats—especially here in Brisbane—who apparently consider themselves and their jobs not only unaccountable but in the realm of the untouchables. My final word on this particular subject is that even directors-general have a use-by date.

Michael Watts, who is a Queensland housing regional manager, was unable to attend because it clashed with a once-a-year annual audit of regional managers but he did provide me with some housing figures briefs which I would like to get on the record:

> The nation building program for this region will result in 141 units and one four-bedroom house being constructed with 38 of the units being fully wheelchair adaptable and 50 being semi-adaptable dwellings. The majority of the new properties are in Toowoomba, with some dwellings also being constructed in Dalby, Stanthorpe and Chinchilla. So 142 properties in total are being added to the social housing stock in the south-west region. It is anticipated that these will be completed and handed over to the department by the end of February 2011. A key feature of the units is that a large proportion of them have incorporated adaptable features which would allow them to be utilised for disabled people.

That is signed ‘Mike Watts’. I will attempt to answer any questions of fact or opinion that you may wish to put on our submission.

CHAIR—Thank you, Mr Lanigan.

Senator BOYCE—Mr Lanigan, you were talking about moving disability into federal control. You would be aware that the current scheme is that aged care would come under federal control with disability under state control. Would you like to comment on how you see that working?

Mr Lanigan—How we would combine the control of aged care under federal?

Senator BOYCE—The current intention of the government is that aged care would be under federal control and disability would be under state control with funding coming from the federal and state governments. But disability would be controlled by the states.

Mr Lanigan—I am sure you would be well aware that there has been an ongoing problem with funding when the federal government gives federal funds to a state to operate disability supported accommodation. There has been a push-pull situation ever since the very first Commonwealth-states agreement came into being, whereby it was quite clearly laid out that the states would be, as you rightly say, responsible for supported disability accommodation. That is not working. The states are not building specific accommodations for people who need whole-of-life support. I am personally certain that the National Disability Insurance Scheme—and I know that is Productivity Commission ground—will happen in whatever form. It will be funded as a social input by the Australian people. So I see that happening, as do lots of commentators. That would neatly dovetail with the federal government taking control of disability supported accommodation and stop the states versus federal push-pull, cap-in-hand approach which currently exists.

Senator BOYCE—I notice you said there are 790,000 people with a disability in Australia. The data that the federal government has and the data that the state government has often do not meet. If you look at waiting lists, or registers as they are called in some states, there are people on there, there are people who do not bother being on there because they think, ‘What’s the point?’ and others choose not to be on there, and yet in the long term all these people are going to need assistance as they age. Do you have any thoughts about how that should be addressed?

Mr Lanigan—The social housing register for this region some two or three months ago totalled 900 people. The Gold Coast register totals 1,500. Of the five priority divisions within those 900, the top 10 per cent, numbering 90, is considered to include those people most in need of accommodation. Quite a few of them are single mothers who appear on the doorstep of Queensland Housing. They have been sleeping either on the street or in a car. Some of them would have a disability of some sort. They are the ones I think you remarked on earlier, saying they are obviously the ones who are dealt with and considered most in need. Social housing in Australia, in my experience—and we have lived in a number of countries—still, for some reason, bears a stigma. Quite the contrary exists in the United Kingdom, where local councils are responsible for the provision of council housing, as they call it. The building standards do not seem to alter very much. Maybe that is one of the reasons why people choose to not come forward and approach social housing.

Our problem is that our son is 45. I am 74 next year—I hope I will be! I am allowed to say, after some discussion, that my wife, Liz, is in her seventies. She has borne most of the brunt as I spent my life at sea—42 years in two navies. I was really not much help, certainly while I was at sea, so she bore the brunt of bringing up Ian, who was born with cerebral palsy through lack of oxygen. He was the first-born of twins. Thankfully, his sister is fine. We have a nice home, we probably could be described as being comparatively asset rich and income poor, as most pensioners can claim. So what do we do? Do we sign up to sell our home early and move into a rental situation in a retirement village, if we can find one? Most rental villages now, because the bottom line is profit, require you to come up with a large bond for entry and exit.

An example of the myopic situation which existed some 2½ or three years ago in Queensland is when we sought advice from Village Life. Village Life is by far the largest developer of retirement villages in the country. They came up and advised us and attended an accommodation forum. Later, not through their doing, TIDSA was contacted by a large financial institution, the ING bank. The real estate manager for that institution on two occasions flew up from Sydney to offer us the long-term lease of one of the four villages in Toowoomba. They got the figures and the demographics wrong initially and built one village too many—they had four. So we had this offer of a 59-unit village in Toowoomba to lease for, I think, $385,000 a year, which is chicken feed in the large scale of things. Disability Services, off the record, assured us that they would fill that from the region and our worries would be over for quite some considerable time. The bank even offered to retro convert four or five of the units to a social area for exercise and other activities. It would have been self-sustainable from a disability support pension and rental allowance perspective. Widows, and many of our members are widows in their late 70s, looking after a son or daughter in their 40s or 50s, could actually have moved into a two-bedroom unit and, when deceased, the transition would have happened smoothly and without additional trauma.

I sat in front at a regional cabinet meeting of the then minister, Warren Pitt, and was not swept off the table but pushed to one side and declared institutional. Against that sort of myopic thinking, what more can we do? You heard described very eloquently by Mike Horan that we really have moved on from that. ‘Institution’ is a grossly overused and emotional term. I would say that what created institutions was not the bricks and mortar; the problems lay in the people who ran them. This in no way reflects upon any support staff behind or indeed any departmental representative behind, because they are the worker bees at the coalface here, but our problem has lain with our capital city, and will continue to do so. This is why I feel really strongly feel the Commonwealth should step in, in concert and dovetailed, with a national responsibility for funding these people, our people, who cannot speak up for themselves.

Senator BOYCE—We have covered some of the accommodation aspects of planning and how difficult it is to find even that part of it. You were talking about an independent spot check system and that the community visitor program currently is not adequate, and I think that would be reflected in evidence we have taken in other states. How would you see that working? Would that be done by government at some level or by organisations such as yours?

Mr Lanigan—Not by organisations such as ours, because you will find, certainly in Victoria, where the system of community visitors is largely run by volunteers—I know you heard evidence from Lifestyle and Supported Accommodation on that subject. Here, with 29 part-time casual workers and 912 visitation sites, spot checking—I asked the Attorney-General’s Department to be represented here today but they are understaffed and could not do so, so we must accept that. But they did give me these authoritative figures. These investigations in Queensland, quite certainly, would happen after the event, after there has been a complaint of abuse, neglect or something like that. We have had personal experience in New South Wales of a similar situation, and it was only through the offices of my wife, who was able to without any notice walk in and see the situation for herself, that it was resolved. I have had a lifetime of inspecting ships and mess decks for cleanliness. We do so on a weekly basis. All the troops know that. We know where they hide the stuff, so we look there first, with or without the white glove. Spot checks are the only way.

Senator BOYCE—Who should be doing that?

Mr Lanigan—A properly accredited, funded and staffed selection of it could be the Attorney-General’s Department, as it is in both states we are talking about. I mean, 29 people part-time. These people have a primary job and the primary job is not community visitor. The gentleman in the department who talked to me about this said, ‘They don’t want a permanent salaried position,’ for understandable reasons. Everybody who is casual get paid more. I know you heard that as a problem within the disability support industry. So a separate subsection or whatever you want to call it of a government department authorised to knock on the door, as these people are. They can knock on the door, within reason, without notice, identify themselves, say why they are there and be shown around whatever area of the residence they wish to see.

Senator BOYCE—Would you see that being sufficient to keep vulnerable people safe in the absence of a parent, spouse or carer who cares about them?

Mr Lanigan—No. They know their limitations. The way I would like to see this problem solved is, as I said earlier, for the support industry workers to be properly remunerated and trained as a career. So many of the support workers are part-time. In fact, there is a service represented here and I happen to know from personal experience there is one lady, who is probably a very nice lady and good at the job, who chooses just to work every second Friday and that is it. That is obviously pin money, that is not a career. You ask a young support worker on or off probation and he or she will tell you it is a job until they get a proper job. That is he problem.

Senator BOYCE—We have heard quite a lot of evidence, and I was just talking to people earlier here today, and it reinforces the evidence that we are hearing right across Australia about turnover of staff, never seeing the same person twice, potentially inadequate training of staff.

Mr Lanigan—We do not expect to have a box of Mother Teresas. You are always going to have a support worker who has had a bad hair day or whatever it might be. So it will range from Mother Teresa if you are lucky to Genghis Khan if you are not. There has got to be somewhere in between.

Senator BOYCE—Senator Moore just said, ‘That sounds like my school.’

Senator MOORE—No-one here from the school—that is good.

Mr Lanigan—Something I hope you will have the time to give the light of day is to reinvest on a small pilot scale in a purpose designed—the term ‘cluster housing’ is no longer a dirty word. As the c-word we can use ‘cluster’ now. In fact, Disability Service did construct a cluster housing facility outside Brisbane. That is the only way we see. Scattering people with individual packages is not financially sustainable. Our kids, as we call them, be they 40 or 50, are happiest amongst their own. They can communicate. It is no good putting them five kilometres away in a house and saying, ‘You’re inclusive, you’re part of society.’ Rubbish. They do not like it, they are not happy, they clam up, they get looked at. People are happiest socialising and communicating and working and living with their own peers.

Senator MOORE—I apologise, but we have run out of time.

Mr Lanigan—I will leave a disk with the secretariat. You have seen this *Four Corners* program before, I hope. It was aired on 15 February 2010 and it is called ‘Breaking Point’. I really would like the whole committee, when you convene again next year, to watch it again, because it just about tells the story; this is where we are at.

CHAIR—Thank you very much for your evidence and thank you for help in organising today; it is very much appreciated.

[2.02 pm]

BEAZLEY, Mrs Anita, Private capacity

COOMBES, Mrs Darcy, Private capacity

COOMBES, Miss Carol, Private capacity

DEVINE, Mr Paul, Chairperson, Breakaway Toowoomba

DIETZ, Mrs Pattie, Private capacity

GERRARD, Mrs Annette, Private capacity

MORRIS, Ms Karin, Private capacity

PESCH, Mrs Donatella, Private capacity

SLOMAN, Mrs Rosemary Joan, Volunteer and Carer, Alzheimers Association

STACY, Mr Peter Brian, Chairman, Warwick and District Disability Support Group

WALLACE, Ms Veronica, Private capacity

WEIR, Mr Robert Arthur, Private capacity

WILSON, Mrs Pamela Jean, Private capacity

WOODCOCK, Mrs Del, Project Manager, Disability Services

CHAIR—Welcome to this community forum.

Mr Stacy—I am the chair of the Warwick and District Disability Support Group, and it is in that capacity that I wish to speak to you today. I have got some information that I would like to leave with the secretariat if I may. Firstly, I would like to make a couple of comments on the earlier speakers today, which I found most interesting. Firstly, Geoff Rowe, from Endeavour, said something I would encourage senators to hold very dearly in your deliberations, and that is that what we are really seeking here is the capacity for people with a disability to lead an ordinary life. An ordinary life is defined as ‘the same sort of life as everybody else’. To me, that is not jingoistic; it is an ideal. If you want to seize on something that defines what we are trying to do for people in our care, it is that. So I commend it to you.

Secondly, my son works as a supported employee for the Endeavour Foundation in Warwick. A comment was made that the retirement of supported employees is being delayed, thus putting more pressure on the intake end. That is very real. Do not discount the ‘tsunami effect’ that was talked about, because it is coming; there are more of these people and, as they get older, they have to have somewhere to go. If there is no way out, there can be no other way in. So, again, I thought that what Mr Rowe said was very appropriate.

I would also like to say something to the people from Mamre about Pave the Way. My wife and I went to a Pave the Way seminar eight or nine years ago—exactly as you translated; you did not know this at the time. We attended one of their planning meetings. The Circle program about building relationships between existing family members, close family friends and others is very important. As they said, we did not do it at the time. We have subsequently done it, and I would like them to know that and I would like you to know that it actually does work. If you take the time to do it—we did not get them involved to sit down with us—it is relatively simple and straightforward, as good ideas often are. I would encourage that. That is not a paid representation, but I thought they needed to know that.

I would like to tell you a little bit about what our group does and what we think. Everybody has been quoting ABS data, and I have a little bit of that as well. Most current ABS data for the Warwick area shows that there are about 1,069 people with a severe or profound core activity disability living in that area. As you would know, a severe or profound core activity disability refers to a serious impairment of a person’s mobility, communication or capacity to self-care. At present, in Warwick, we have overnight respite facilities for three people at any one time. The place for the third person only became available a week or so ago. We have no emergency respite, limited in-home respite, no emergency accommodation and no effective options for people with high needs. To access any of those facilities, any affected family must travel to Brisbane or to Toowoomba, and clearly this is inadequate. In terms of longer-term accommodation options, there is one house run by the Endeavour Foundation and three others through Community Options—that is, Queensland Health—which in total house some 20 people. By the way, 11 of them are in one house. They move in with people with low- to medium-care needs. There are no options for people with high-care needs. We are only an hour away, but that hour is a long way to drive.

Ageing carers, in our view, are the most disadvantaged as there is no clear plan for their relief. I guess that is what you are working on. Our group firmly believes that any program that is developed to address the needs of ageing carers should include three things. Firstly, a properly constructed and funded transition program which allows their charges to develop the skills and confidence to begin the process of moving away from home. To be effective, this transition program should begin when the person with a disability has reached an appropriate age, not when the carer triggers some other age threshold, which is currently the case. We believe that the creation of a type of lifestyle centre which provides the social network to support people with a disability when they can no longer work is mandatory. People who reach retirement age would be examples of that. This would lend itself to other things: people coming out of school, people trying to find something until they determine what they are going to do; people in supported employment—all those people need something to do other than sit at home. The third point is that these people have to have, in our view, the ability to become a stakeholder in the future. When I say ‘stakeholder’ I mean that. This would be regarded as a moral right, as for anyone without a disability working in Australia, but it is out of the question for those people with a disability. There are plenty of challenges here, and we talked about those quite a lot: advocacy issues and funding issues. Not everything has to be funded by the government, but the people who are interested in the program must have the opportunity to be a stakeholder, and currently that is extremely difficult to do. There are some challenges here but also some long-term benefits.

Within the package that I have for you is a letter from a lady who would have come today but could not organise herself in time. I would like to include that with the information and pass it to the secretariat. I would like to thank you for your time and for the opportunity to speak to you.

CHAIR—Mrs Pesch, would you like to make a statement?

Mrs Pesch—Hello to all of you who have the courage to face your heavy responsibilities when you find that your children a disability. I have been a volunteer for 33 years in disability. Firstly, when my daughter was about 17 in Roma we formed a small group which was overtaken by Rotary. Then, a bit later on, a coordinator of disability services came out and I put my hand up as a volunteer to Lorraine. From that, I learnt more and more. I have been on bus rides with children. On the funny side of it, we went to Camp Cowa. My daughter was not among them but, coming back, Lorraine was the driver and I was the carer. There were 17 children, and when you get to Roma and Dalby from Caloundra it is pretty hot. So she said, ‘Let’s get them some whippy ice creams.’ If you try to keep seats clean of ice cream with 17 kids with disabilities, it is quite a job but a lot of fun.

I just want to say—I really don’t know how to put it—it is about the people who are young in age. I will try and give you an example. My daughter Lizzie is 44, was epileptic at seven and has only been stabilised in the last 18 months. She was complaining of pain in her feet and her doctor in Toowoomba got X-rays to find out she has osteoporosis, which we are trying to stop developing as best we can, and this week I moved to Toowoomba from Goombungee because I feel it would be much easier to access things that will benefit my daughter.

I do not know what else to say except I thank you for listening to my speech. I am not used to talking to a group of people, but may you all have good Christmases and happy ones, and God bless all of you in your challenges. Thank you. I cannot talk any more.

CHAIR—Thank you. Karin Morris?

Ms Morris—Good afternoon. Let me first introduce myself. Excuse me for staying seated but I cannot stand. I am 66 years old and I have been a carer for my 43-year-old son, singly, for 33 years. We both have extensive health issues and, before I go on to anything else, I would like to echo a lot of things that Mr Lanigan mentioned earlier, particularly in relation to cluster housing. Having lived in New South Wales until 10 years ago, I have seen the effects of so-called group houses on people who are totally isolated because their neighbours will not accept them. In Wright, I think about 90 per cent of residents decided ‘not in our backyard’, which is something you were talking about earlier.

A positive thing in New South Wales was a program called Community Options, which was a brokerage service to which people like me would go. Community Options would source and partially fund the appropriate service for each client.

In relation to your terms of reference, as to inadequacies in choice, I have extensively researched but still find that I do not have the correct plan for some things. We have been on a priority 1 for eight years, but that has not done me any good. As to quality of life for people with a disability and their carers, people with disabilities need to go on holidays too. So where are the holiday options? DoCS in Sydney can run them, so why can't we? The third term of reference is 'the types of options that could be developed to help people with a disability to plan for the future'. Early diagnosis is important. My son was not diagnosed until the day before his 21st birthday. That makes planning rather difficult.

Early intervention and provision of appropriate education are still lacking for a lot of the grey area children, like fragile X and autism sufferers, who to all intents and purposes look 'normal'. I stress the word 'normal', even though I do not know what that is. When a person looks disabled, people may make more allowances. With our people, the grey ones, because they look relatively normal, people immediately think 'pervert' or 'weirdo' because they might run down the street having a conversation with themselves and flapping their arms around—and everybody takes a very wide berth. Even in schools they are not appropriately addressed.

What else would help carers with the question of: 'What happens when I can no longer care?' I would like to take my son into a retirement home with me where, as I progress through, he could progress through low care et cetera as well, so that, if anything happens to me, he is already in a place where he is used to the people, where they know him and where he is comfortable. Fragile X sufferers do not handle change very well. So the shock to a Fragile X person of not only losing their parent but also losing their home is terrible. The emotional effects are traumatic.

As for residential places, we have tried that. I lived in New South Wales until 10 years ago. One experience in residential was so traumatic that I cannot even get my son into respite now. He totally refuses because of that traumatic experience. One thing that was mentioned today was a village model. That was proposed by Crossroads in Sydney about 25 years ago. The difference there was that they wanted the carers to go there with the family member, but that was knocked on the head as well.

I am dismayed at the lack of options for people with disabilities. We allow people to go into various groups but, when people with disabilities want to group together: 'Oh, no, you can't do that; that looks too institutionalised.' Facilities like Endeavour are fantastic and I think they should be encouraged. For somebody like me, Breakaway—which has been extensively discussed here—has been a lifesaver. I have made a lot of plans over the years but, like a lot of other people, plans can be destroyed through illness, divorce, domestic violence and other unforeseen things—and all the best laid plans of mice and men go down the drain and you start all over again and yo have to come up with another plan. If you ask my son what his plan is he will tell you that his plan is to stay home with mum. As he says to me, 'You had me; you're stuck with me.' On that note, I think I will finish.

Mrs Beazley—Good afternoon, everyone. I became an instant carer five years ago when my husband collapsed of a brain aneurism and now has an acquired brain injury. There are things that would have helped me greatly through what I have been through. Before a person with an acquired disability—meaning someone who is disabled during life and is not born that way—especially an acquired brain injury person due to them being unpredictable, leaves a hospital or a rehabilitation unit there should be the necessary information, help and assistance, respite, home care et cetera put in place, ready to go, from day one to assist the new carer.

Why is it that someone can be released into the care of someone with no training, no first aid, and no medical knowledge of what they will have to deal with? I would like to see a carer trained or taught and provided with information to see if they can cope and understand what they have to deal with before a person is released into their care. I would also like to see the person who will be the carer have the opportunity to say yes or no to the life-changing decision of being a carer and there not be just an assumption that that person can and will cope and do it because the person in question is a loved one.

Respite is a vital part of a carer's life. This is when we catch up on things—for example, housework and forms—socialise a little and, if we are lucky, afford a holiday for a few days. As the population of acquired disabled people grows due to medical technology, respite facilities need to grow also to keep up with demand. Breakaway do a tremendous job here in Toowoomba, juggling the ongoing demand which is increasing all the time. They have the criteria, trained staff, paper work and all the aspects for care—from diet, medication, medical history et cetera—in place, which makes a carer feel at ease and know their dependant will be taken good care of.

I would like to see facilities for permanent residence for those who are ageing when the health of a carer is a problem or for those who simply cannot cope. I would like to see more facilities like Breakaway in our area to ease the stress on carers. These facilities are desperately needed for the acquired brain injury disability area. They do not fit the criteria for nursing homes, hostels et cetera and require a constant carer. For those disabled people who are able to work, there is a need for facilities like KBH Enterprises but in different fields to cater for their needs and abilities. This gives them a sense of belonging, something constructive to do and they feel they are contributing to community and society. If a carer is in an accident, needs to stay in hospital for whatever reason or has an emergency situation in the family where they cannot look after the disabled person, what happens to them? Where do they go?

If a carer is in an accident, needs to stay in hospital for whatever reason and has an emergency situation in the family where they cannot look after the disabled person, what happens to them? Where do they go? The children—and I have four—in a family with a person with an acquired disability, especially a brain disability, need to be considered. The other parent usually becomes the carer. This changes the whole structure and balance of the family. They miss out on family time and social and community things; they struggle to be accepted by their peers; they also struggle with learning the skills of socialising and communication and what is acceptable and not acceptable. Children who do not cope with acquired disability in the family can have depression, be withdrawn from society or even become problem teenagers. With one parent being a carer and the other parent being disabled, who do they turn to for support and help?

The disabled are not the only ones who need help. It is the carers, like me, who struggle every day and hope the next day will be better for them, their family and the disabled person. To help us all, you need to increase the funding and facilities—more funding for facilities for respite care, supervised work sites in different fields and permanent places to cater for brain injury disabled people. As medical technology advances, the number of acquired disability people will increase and the demand for these facilities will also increase. Something has to be done. Please help us.

Mrs Wilson—It is nice to have the opportunity to say a few words. I am just talking about our particular situation as a family. Our son, Dan, was born 36 years ago with Down syndrome. Our aim as a family has always been to provide for Dan the best possible options—to give him choices, to develop him in the best way we could as a family to be his own person. When we moved to Toowoomba he had just turned 21. By the age of 23 he was saying very clearly, ‘I want to live in my own home.’ We have been able to provide that, which is very fortunate for us and for him. He had a couple of trial situations first, but then we were able to buy—just on the turn of the property market—a little house not too far from us. He moved in there 10 years ago.

He was given a little bit of block funding support from a couple of support services. That seemed to be, with all the support we offered, an ideal situation until his health and my health started to falter. We realised that we were getting a bit older. Along came the most wonderful thing: Community Living Initiative funding. That was at the beginning of this year—absolutely perfect timing for us. If you have not heard of it, this in an issue for all of us. Families all through today have said: where do we get information from? Where is it when we need it? Where is the up-to-date information? I say loudly and clearly: Community Living Initiative funding is possibly one option. We applied for and have been granted the funding. Very soon we hope to get right into the swing of using it.

How do we plan to use it? We will, in the main, employ a facilitator to assist and to connect to the community to really look at what Dan’s interests and skills are and what is available in the community. This is to link him into those options so that he will be able to be maintained in his own home and out there in the community as well while not just following his interests but contributing. We have already had a barbecue that he planned with the help of this facilitator just a weekend ago. He invited his neighbours. They know him but they have not invited him to their house. He has invited them to his house first. It was a very successful first barbecue. Living in the community is not enough. You really do need to connect as well. Besides doing the active running around, finding and connecting, the facilitator will be a vital member of Dan’s support circle. I did attempt to establish a support circle. Although it might be simple for some families, this head of mine was not coping too well at the time and feeling pretty vulnerable and could not take one more load or one more thing to establish a support circle. So we are going back through that process. We know how wonderful it can be because we have had a little taste of it. That is going to be a major part of maintaining Dan in the community with support circle members.

I want to say a couple of things about some concerns about it all. I will go back. No. 1 is the information about actually having funds available like this. Okay, it is new funding, but it is another kind of repeat of information not being available to families as soon as it is there. It is the issue of why bother planning if you do not know there is something you can plan for. It is not an easy process for a family to fill in an application form like this and to do it well enough that it is successful: to have the supportive documents and a well-written personal plan with the vision stated clearly so that you are convincing the committee who evaluates the application that this is a worthwhile case. While it is absolutely wonderful that it is flexible—as it is—the expectation is that families will self-manage the funds. But at 65 no way am I going to start managing funds and employing people—no way! So the option is to ask a support service to manage the funds for you. You pay some of the funds to that support service so that reduces the amount you have left for active use.

It does not actually solve all the problems. I still feel as a family—and we are getting older—that somehow we still need to manage Dan’s financial and medical needs. We are still working on that, particularly how we find the person who will pick up on when his kidney disease develops to dialysis stage. Who is going to manage those kinds of things? So there are the two things, the financial stuff and the medical things.

As a finishing point, I do think that somehow you people out the front there have got to come up with a magical solution, because what you have got to do is meet the needs of the most incredibly wide range of needy people. It is really an impossible task. But choices are really important to families, so it is a matter of not expecting all families to have their needs met with one model. There really does need to be that flexibility. Thank you very much.

Mrs Woodcock—Hello, everybody. I am a project manager for Disability Services in Brisbane and I am working with my colleague here, Bob Bright, on doing a review of a program that was mentioned earlier by Mr and Mrs McKenzie, the respite for older parent carers initiative. My role and Bob’s role is to go around the state and talk to older parent carers, the people with disabilities who are supported by them, the people who are dedicated to delivering services, the dedicated officers who are employed by the services but funded through the department—through a bilateral agreement with the federal government, so it is co-funded—and also our own Disability Services staff. It is to find out whether or not this initiative was effective, whether it was meeting the needs of the older parent carers, whether there were any gaps—and if so what they were. Then it is to come up with a series of recommendations that can be put forward, to perhaps put a business case together to get additional funding.

It has been pretty obvious to all of us when we have gone out there that additional funding is necessary—and you have talked about that. But one of the key things that have come out here today—and the lady in the lilac blouse hit on this very clearly, along with others today—is planning for the future. One of the big gaps we have is that the older parent carer initiative funds planning for the client, the person with the disability. We have a huge gap here. That is only supporting one part of the overall scheme. The family needs a plan too, because once the person with a disability has moved from the home into alternative accommodation the family is dealing with grief, with loneliness, with guilt and with a whole series of things that they do not know how to cope with. On top of that in some instances families—and I have interviewed over 120 in the last few weeks around this state—are finding themselves in a situation where, because they have been caring all their lives for their loved one, they have actually lost contact with their friends and their families—because they are older and are dying off—so they do not have that informal network anymore and they do not know how to reintegrate into the community. That is part of the planning that we believe is going to come out as a recommendation in our report: parallel planning, not just for the person with a disability but for the family as well.

One of the other things that came out really clearly was that an assumption was made that older parent carers are ready to let go. That is not necessarily true. The statistics from what we have done, and we are just doing the analysis now, identify to me that only 29 per cent of the people that we interviewed are ready or are even considering letting the person that they have cared for all this time and loved move out. When you ask the client, the person with disability, what they want, they see it as 50-50; 50 per cent of them are ready—‘We want to go and live with our friends’—and as for the other 50 per cent they say, ‘No, we want to stay living with Mum and Dad’. So some of the things that have been coming out are really crystal clear that planning, as you have been talking about, is absolutely critical.

There are two things that I really came here today to talk about. I want to raise them briefly. The first one concerns when I was talking to some families who were living on properties—which means they are considered asset rich—and were getting money to care for their loved one. Because they are asset rich and cash poor, the amount of carers money is reduced. They are finding they are on the bread line. They do not have any income and they are really finding it tough. That is the first point that I wanted to bring up on behalf of the older parent carers I interviewed.

The other is about where a family has in fact purchased a home so that their loved one can move into it on their own with or without community living initiative support. I have with me today Robert Weir, who is the next speaker. He has gone through this and he has some points he would like to really make. One of the things he missed out on was the first home buyers grant, simply because it was impossible for him to purchase a home in the name of his son because his son could not be trusted not to sell that property and waste the money.

Mr Weir—Good afternoon, senators. I live over the Dividing Range, which makes things difficult. The tyranny of distance comes into it a little bit. I find this a little interesting, because it is headed ‘An inquiry into paying options and services for people ageing with a disability’. I have always aged with a disability; I was born with a disability and I have put up with it until now. But, added to that, I have a son who for the last 28 years has suffered from schizophrenia. His mother, who now looks after both of us, finds that very, very difficult. Despite what I was told by one of your guests this morning, I regard mental illness as a disability; others clearly do not, but I hope that you do.

We worked overseas in various countries, partly selling duty free beer to Australian servicemen—and that went down very well; it was 40c a pint! But we did not find anything adequate. We tried to, and we went around to places. Michael went into a flat in Toowoomba but the was not too successful. The people around were into marijuana and goodness knows what else, so that fell apart. So then he came home again and lived with us. And that was not too happy either. He is now 46. I do not agree with what he says half of the time and he certainly does not agree with what I say, because there is a considerable age difference.

So we continued with what we had started overseas. We had funds in a trust fund for him which we had garnered by gathering together and selling off what we had, thus reducing our assets but giving us the opportunity to purchase a house for Michael —and that we did. But I could not apply for the $10,000 grant for first home buyers, which he in fact was, because, as Del said, it was bought by a trust, and that is a separate legal entity. Although I asked a member of parliament to make representations on my behalf and on Michael’s behalf, I was told that I could not possibly do that. I would like to read you a little bit of the reply. It says: ‘The government cannot make an exception … I have to confirm that there are no specific CGT concessions for people with disabilities compared with other taxpayers. The government considers it inappropriate to discriminate against taxpayers whose only source of income is wages or salary or a superannuation payment and who may have little or no capital assets. Furthermore, it would set a precedent for capital gains tax exemptions on the large range of issues where people believe they are disadvantaged by their circumstances.’

Well, that is quite right: there are no specific concessions for people with disabilities compared with other taxpayers. But then people with disabilities are not taxpayers. They cannot work and they do not get a wage. They simply get what the government, in its generosity, gives them by way of disability support pension—and you cannot buy a house on that. We then changed Michael’s house to get another house closer to us, and we had to pay capital gains tax on the modest profit we made on the first one. Again, there was no concession; to get one, he had to be absolutely entitled to the property, as against the trustees. Well, if he is absolutely entitled to it, he will sell it. He drinks and smokes and he has nothing else to do. So what do we do?

Thanks to Carers Queensland, Community Services, Anglicare and another agency I have forgotten, we have had some respite. My wife was taken away and given a week’s holiday, which was much appreciated. But she and I have not been on holiday for the last 30 years because we cannot leave Michael. So what do we do? She goes on holiday and then maybe I go. That is how we are placed. When you have got the situation of ‘how are you going to plan?’ what can you plan for?

One of the first speakers today said, ‘Perhaps you should be out of the way and then you won’t need to care.’ Well, that is quite right. But the trouble is that that gets to be true: I would rather be out of the way because I do not need the care. But that has had to lead to me having some treatment—because it all gets vastly too much for you.

Michael lives on his own and he comes around every day for a meal. If he does not do that, he will not cater for himself. He buys his beer, cigarettes and whatnot, but he lives on two-minute noodles and boiled rice. And, not surprisingly, he loses weight. So his mother gets worried. Somebody else said that what disabled people want is to lead a normal life. But Michael cannot lead a normal life; he needs care, and there isn’t any. This is compounded, of course, by the fact that we are in a country town. But that has its advantages. The people in our country town know my wife. They do not know me; I have only been there 20 years, so they have no idea who I am! But they know my wife because she was brought up there. So my wife gets to hear what Michael is doing through her friends. They do not tell me, but Thelma does tell me. They look after him in a way, so she knows what he is up to. But it makes it very, very difficult.

The next birthday I will see is around about my 80th and my wife is well into her 70s. All I can hope now is that, when we die, somebody, somewhere will pick up Michael. If he is put into an institution, so be it; we will know that he is safe. Because his illness varies, if he is not put into an institution he could end up on the streets. We do not want that, and I am sure you people do not want that. Thank you very much.

Mrs Gerrard—Thank you for the opportunity. My husband is at home today looking after our Centrelink bits of paper for our intellectually disabled family. I am the mother of four intellectually disabled adults with ages ranging from 45 to 50 living in Toowoomba in various accommodation situations. We had to make that decision over the years because if we were going to do any sort of caring then we needed some time to care. Our family members are involved with different service providers as they all have different life choices. We are involved with Disability Services Queensland, Breakaway, the St Vincent de Paul Society, whose two homes Mr Horan spoke about earlier. They now have six, not two. The others are the Endeavour Foundation and Quality Lifestyle. So we have quite a lot of experience with service providers.

I wish to make the comment that not all intellectually disabled people require 24-hour in-house supported accommodation. There are people living in private rental in the community with limited support. If services could be developed, like the number of cottages model along the lines of rented senior villages or cluster housing, each resident having their own cottage or unit, the training to live as independently as possible over time needs to be done in that situation. They need 24-hour management but this is the difference: management has to have disability qualifications, not just a management. They need to be aware of the clients they are looking after. They need to have disability qualifications, as residents are vulnerable. Each resident needs some funding for a support service for a daily check on health, bills that need to be paid, community access, doctor and dental appointment support, not just making appointments—they need to be supported because they will not speak up when they get there. Then more people can get service that they need and it will require less funding. These are the people who may be involved with the police because their problems escalate before issues are dealt with while they were manageable. These people often are easily led and taken advantage of by the community at large.

Training of all staff should be an essential, and closely monitored and checked that the training is done and ongoing, not just accept what the service provider says. They will write it in their policies and procedures but if you go and check on the people they are employing and check if they have done their training, it is not being done in a lot of cases.

I would comment on what was said by the Endeavour person. Some years ago here in Toowoomba a number of Endeavour clients working at the sheltered workshop were moved out, not by choice, as they did not reach the productivity level that was required at that time. They went into two activity centres which were federally funded at the time, so that did not cost them to attend. This funding was then passed over to the Queensland state government and each client now pays $85 for a five-day week just to put their foot at the door. So these people are living on disability support pensions; they do not work because they were declared unproductive.

There was a comment about taxation earlier. Many parents who have intellectually disabled family members cannot work. They have not had the opportunity to build their superannuation like most other people have done and do not have that to draw on. Your life is tied up with Centrelink, medical services and, in our case, the Public Trustee—we have two members who are with the Public Trustee. Your whole life is tied up with your family members. We talked about a circle of support. We do not have a friend in the world. Our life has been around our four intellectually handicapped family members. Our kids know more people in Toowoomba than we do. Every time they go out, they get a wave. ‘Who is that?’ ‘They are with Anglicare’ or ‘They are with Endeavour’ or other people that they know. We know nobody. We have no friends. We have no communication with others. Our whole life has been tied up with looking after our family members. We are all in need of help. But we do not all fit in just one box. There is plenty of disability out there and there are different needs. But we are all heading to the grave and too bad what happens when we are gone. We just hope that somebody will pick up what we have left behind. Thank you, everyone.

CHAIR—Ms Wallace.

Ms Wallace—I do not know where to start. I had a phone call late last night from a friend of mine in Roma. I have a wide network of friends with children with disabilities because that used to be my life. My son passed away in September 2006. He had a sibling, my 22-year-old daughter. Siblings suffer as well. I agree with what everybody is saying, though there are a few things I disagree with. We do not need to be put in boxes. I was once involved with the South-West Queensland Regional Disability Council. We all pushed for a thing called ‘train the trainers’, which was a good idea at the time but it never really came off as we had wished. There are some wonderful people in the community who have great hearts. But there are a lot of people who need a lot of educating, including doctors, nurses and heads of organisations who really need to walk the walk before they talk the talk. Thank you.

CHAIR—Mr Devine.

Mr Devine—I am chairperson of Breakaway. For those who do not know, Breakaway operate the respite older parent carer program in Toowoomba and the Anden project, an accommodation services initiative which has six residents. The first thing I want to address is what Mr Lanigan said about support staff. I concur entirely with what he said. The level of competence of support workers is extremely important. As a person with a disability for 26 years, I thank my lucky stars everyday that I can verbalise my thoughts and that I have the intellectual capacity to manage and support my needs. I came to Breakaway 5½ years ago because I was concerned about those in the community who could not do what I can do. I am not necessarily concerned about the number of hours support staff might work. It does not matter how many hours they work, but they have to have the passion and the dedication. That is all that is needed. But the support workers do need to be properly trained.

At Breakaway, we regard the level of support we provide as very high priority. We have an expression, ‘vertical cohesion’, which obviously means from the very top to the very bottom we must all work together to achieve the best possible outcome for our clients. Morale is very high in our priorities and we work assiduously to ensure that we maintain that at all times. The stress levels that the families and the carers feel on a day-to-day basis must be a major concern, and it is what we need to do to care for them and their family members.

The Anden has been a great success and we have been very pleased to be involved. It has been very well managed by David and Marta. They are exceptional people who do an exceptional job. It is wonderful to see the change in the carers from the time that their family member joins at the Anden. In many respects, they look 10 years younger. The stress levels have disappeared. They are happier and are comfortable, and it just highlights what they have gone through all their lives.

There is obviously a great demand out there for residences like the Anden. Going on the discussion, we all know the cost involved in developing something like it. What we are talking about in Toowoomba is enormous but, when you extrapolate that across Australia, the resources required are astronomical. So what are the solutions? One of the solutions really is that we do have to think again and put more resources into respite. We have spoken here many times today about how often people are only supported when the straw breaks the camel’s back and the family members can no longer provide support.

There are many reasons why and when people go into supported accommodation. I thank Mrs Woodcock for her statistics showing that a lot of carers, a lot of families, are not in a hurry to have their family member go into supported accommodation, which is something I have long suspected. Think of it this way: because they do not have the resources and they are physically unable to do it, if they are forced to put their family member into supported accommodation years before they need to—I hope this does not sound too insensitive or too crude—the community then has to support that person for 10, 20 or 30 years, which is an enormous expense. If the family member can stay in the supported family environment, where everyone is happy, for as long as they want to, that must be the ultimate solution. I can use some figures to support this. The Anden supports six residents. It has an annual budget of $449,000. Our older parent carer respite program has 80 registered people on its books, and more than 40 of those go in and out of care in our residence throughout the year. Those 40 people are supported on a budget of $228,000.

We are restricted by the criteria as to how much respite we can offer people over that period. My suggestion would be that if you relaxed that and allowed families to have much greater respite—instead of one month a year, make it two months a year, make it three months a year, whatever the case may be—you will find they will be much less stressed. You will find that the families will be happier. You will find that the resources needed to develop supported accommodation will be negated—instead of building one house a year you would build one every two years. So I think the allocation of funds and resources could be better utilised, and basically I support everything that everyone else has said here today.

Mrs Dietz—I want to add to what a lot of other people have said here today. Listening to Anita, I found it quite sad and quite frightening that she is actually going through what we did as parents 43 years ago, when you were handed a baby and you were sent home or it was suggested that you institutionalise that person because there was no support. Also, the fact is that the family would break down and you would either put them in an institution or you would just love them until they died. I think it is really tragic that in 2010 the same story is being repeated to this family. It is nothing short of an absolute disgrace. And she is right about the siblings: they have and will suffer through this, and she is not getting the support. I find that absolutely deplorable in 2010.

Another thing I would say, getting back to making your vision, is that that probably for us has been an absolute goldmine and a wonderful thing to do. Tricia is 43. She has her own house with State Housing, she shares with somebody and she does have individualised funding. I can only support what Jeremy says, that individualised funding gives you flexibility and it also gives you freedom. I am not ‘grateful’ for the funding—I do not think that as a citizen I should be grateful for something that I think should be right as a citizen.

My daughter was a noncitizen when she was born. She is a great employer: she employs staff, she lives locally, she goes to the local community, she uses the local doctor, she goes shopping in the local area. Her pension, within probably three days, has circulated within this state. I have no offshore funding. I do not have any bank accounts offshore. So Tricia is very, very cost-effective for this country. So are a lot of people with disabilities and so are people who are retired and so are a lot of aged people. Individualised funding actually creates a huge economy for this country. I do not think we need to be grateful for that. I have worked, my children work and the siblings of others work—so, no, we are not grateful.

I have great concerns for younger carers. I see the government is now funding up and Carers Queensland are funding up things for younger carers to become—this is the most unbelievably tragic thing—the next horses that will carry this huge load. We have got young carers that are looking after parents with mental illness or disabilities. We will give them a holiday, and we are actually thinking of giving them a pension. They do not even get the education they should, they will grow up feeling it is their job to take on that role, and we are encouraging that. These are the siblings or the children of people with disabilities. Where are we going with this stuff? We are saying, ‘We’re looking after the carer.’ For what? Looking after the carer till they get to where we get, where we all fall off the perch? And then we get another lot and train them up. What are we doing? I have real concerns for these young people—and that is your children as well: those siblings who will be reared to think, ‘That is my job.’ Will they look for another career? No, because they are being groomed to be a carer. We need to look at that seriously.

I have a few things here that I really wanted to discuss. The fact is that we are including people. We are including people because, yes, we were excluded. Now we have all these inclusion programs including people into life. That in itself is just disgraceful. Tricia does not have an easy run or an easy road. She is sharing with somebody who did not have any funding until the initiative came along that Pam talked about. He is a young gentleman who came out of a very abusive situation and became a friend of the family. They share that house together. We have managed to get that little bit of funding for him and the organisation that cooks and things does that meal for him. It is very cost effective living in the community. We did not have to do a whole lot of walking around talking to neighbours. It is a group of units with a mixed group of people. There are young families, elderly people, a paraplegic guy and everyone in the neighbourhood knows where the units are. There are choices for everybody. As Tony was saying, there are choices for people who want to go into retirement villages or cluster housing and they should have the right to do that. As far as individualised funding I believe personally that it is very cost effective because it is flexible enough to be able to employ a lot of people. As I said, Tricia is a great employer.

As far as the certificate staff, certificates III and IV sound great. I would like a certificate for common sense because it is not very common. When they are training staff, I would like to see a little bit of common sense. Do not send me a staff member who is an ex-prison officer because in all reality—who doesn’t eat meat? I do not know where that training came from. I have a bit of concern about that. There was one who did not turn up because their car broke down and they rang Tricia up and said, ‘Are you okay?’ She has an intellectual disability and she says, ‘Yes, I am.’ Also there has been an example of getting her partner who has a disability to give her medication and that was done over the phone. He cannot read but she can. We have a lot of issues with staff training.

I suppose deep down I feel that was Tricia’s choice. It took a long time. She is 43. She always wanted to live as her sisters lived. It took us 14 years for state housing to come up and we walked in without any funding at all. But we were not moving. It took that long for her to get that home. She is now in the community. We still have our ups and downs. She has circles which I cannot speak highly enough of—a circle of neighbours and a circle of friends. Her family now support her in her circle as well. I just feel for Anita that the department need to jump in here really quickly. Those siblings will become another crisis—not just her but her family. I would like for you to take that back and move really quickly with it. Thank you.

Mrs Sloman—I am going to try to stick to my notes because a lot of it has already been said. But I would like to propose to the Senate committee today that they continue to be open, willing and aware of these issues. I propose consideration be given to areas of psychiatric disabilities, mental illness and co-morbid mental illness. Mental illness research now shows that in some cases people develop early onset dementia.

I am here for myself and also as the mother of a 34-year-old girl with mental illness who has shared care of two boys. I take your point about kids being carers because I have just been informed that my grandson can now be the carer. I am going to step in somehow. That goes to my next point that I wish to raise with the senators here today. Carers and parents need support and funding via the carer allowance because distant carers, like me, have roles in disability and mental illness even when we are not all living in the one town.

I have had to split myself in two for the last number of years. My husband resigned from his employment up north and, likewise, I did, to move into my mother’s home here. She was diagnosed with Alzheimer’s dementia—about mid-range. I say that politely, just to define where she was at. I accepted a full-time nursing home here in Toowoomba a few months ago, and that is working out. So far it is okay. There were many teething problems. I am still is doing a lot of the running around for my mother’s appointments, which I choose to do, which causes more stress on me when I have to care for my daughter via the phone. Many times she would be in a foetal position in the corner of her room and I have to talk to her, support her and nurture her to get out of that position and get out of the house. I do not wish to go on to that. I just wish to say that, hence, my Newstart and carer payment nearly all went on phone calls or flying up and back for emergencies. As you would know, you do not get the carer allowance once your loved one goes into a home. Getting a little bit of carer allowance certainly would encourage independence and growth for the care recipient and would maintain the informal support that I and other families very much provide.

Mrs Catherine Raju had thoughts about a funded gym membership for disabilities and mental illness. I consider that very important. From personal experience, my daughter had to pull out of that. She could not afford it on the disability pension, plus pay a psychologist fee for her son. I tried to pick up that on my pension. If we could give people some avenue for physical exercise as part of a group, I think that is crucial, instead of them joining a membership—being coerced, I should say—and then having someone ring up one day to say they cannot go because they are hiding in the corner of the room. They cannot get out of that membership, as you would know from your own experience. I just wish to affirm what Mrs Raju said to the committee earlier.

As far as cert III and IV goes—hallelujah! Regarding cert III and IV in aged care settings for specific dementia wings, I have great problems with that. They are not trained in dementia at all. Carers are the ones who do the role in the home. I do not know where we take that. It is a big area. I resigned from work by choice to care for my mother here in Toowoomba. I raise this as a thought for the committee. When you resign from a job and take on another profession, as a carer within the home, you also have to resign from professional membership boards. There are the registration fees. You cannot afford to keep up with those registrations and professional development points. I think you would know what I mean when I say that. Therefore, when you put your loved ones into nursing homes, there is no job for you. You go back on Newstart, and that is okay.

I am doing voluntary work with Alzheimer’s dementia and I am loving it, but I am finding it is very stressful when I have to tear myself from the distance caring role for my daughter up north and give my mother the option of going out with family for her medical appointments. If anyone says it is easier when your loved one is in a home, I say it is not; it is just as hard, if not more demanding on you. Thank you very much for listening to me and allowing us to take the time to speak to you.

Senator BOYCE—How old is your grandson?

Mrs Sloman—He has just turned 12. I understand that 12 is the age where they can get the carer allowance, or whatever, to look after loved ones. Is that true? Does anyone know if it starts at the age of 12?

Interjector—It is started at a very young age.

Senator BOYCE—Who says you can be a carer? Who was it who decided that?

Mrs Sloman—The system, obviously—the system being Carers Queensland. I got that information from them. That is in the north.

Senator BOYCE—But has some government body said that you should be the carer now, or what?

Mrs Sloman—I am not aware of that at this stage. I have only got that information in the past week.

Senator BOYCE—We have an answer at the back there.

Ms Wallace—I do not think they get a payment as such. My daughter actually looks after the young carers; she does it as a voluntary thing. But they are trying to get the stats together as to how many children are looking after either siblings or parents. I know that in our area alone, just in Warwick, Katrina looks after 18 children that are under 18 and look after either another child or a parent.

CHAIR—We have a little bit more time. Senator Boyce has a question for you.

Senator BOYCE—It has been raised by someone here who did not want to speak that transport is a really big issue in regional areas, particularly small towns. Are there any comments that we could have on the record about that?

Mrs Woodcock—I am happy to make a comment on that one, because that is one of the things that came out loud and clear when we were travelling around the state. You have carers who no longer have licences and who are expected to take the person they are caring for to medical appointments and to all sorts of other things. They have to use taxis. Oftentimes they are 30 or 40 kilometres out of town. It is very, very expensive. It is not only that but also the distance from where they live to the support or service they are going to get. This came up, and it is really high on our priority list. It is one of the things that we will be putting in our recommendations—that it has to be addressed—because the carers just cannot keep footing the bill for this out of their allowances. It is just impossible.

Ms Wallace—Just on transport, apparently Yellow Cabs kicked up a big stink because of some of the service providers. I have lots of issues around transport; sorry. Some of the service providers were transporting clients because they had the vehicles and the clients could not transport people in wheelchairs and things like that in the community. There has been a whole can of worms opened there, because there are a lot of rules and regulations about who you can transport and who you cannot transport. I think everything has yet again got way out of hand. Where is the common sense? I know you have to be insured and I know that people have to be responsible, but taxi drivers are transporting people with severe disabilities and they have no training. They are rough, and some of the vehicles are not up to standard. They do not have blue cards—not that I think much of blue cards, but anyway we are not going there.

Mrs Dietz—What I would like to follow up on with the young carers is that, when I went to the carers conference down at the coast, there was a row of young carers that came down to that conference. They were probably from about 11 or 12 to about 15. They found it very difficult when I stood up and said that. The fact is that the young carers got very defensive, thinking that they want to care for their parents and that that is what they want to do—they have to look after their families. They are very fearful that their families would break down if they were not there, which is probably exactly what would happen. They feel at risk. My concern is that they will take this on willingly, and that is what they are saying: ‘I know, but I want to do this because I can do this for Mum,’ or, ‘I look after my brother.’ I think that is where we have really done the wrong thing here. Of course as a family member they are going to say everything is okay, and for them it does keep their households together. But the tragedy is that a sibling or a child of that age has to keep a family together, and there are no hours coming in so they can be a child.

Some of them do not even play; they just come home and get into it. That is what they do. They are like little adults. They are losing their childhood. But they feel threatened that they will be told they cannot do this anymore and they will not be given the option of some support coming in. That is the worry. They really reacted greatly at that conference. I stood up and said, ‘They’re children!’ But they said, ‘No, we want to do it.’ I can see why. It is because they are very scared that their family will break down—and without support it absolutely will break down.

Mr Lanigan—I asked that Centrelink be represented here today—they could have answered a number of questions of fact—and I was assured that they would be represented.

Senator MOORE—There was a representative here.

Mr Lanigan—In that case, she has gone. It should have been the regional manager.

Senator MOORE—I take it Centrelink did not advise that they were here.

Mr Lanigan—No.

Senator MOORE—Their attendance, then, was not very helpful.

CHAIR—We can put questions on notice to Centrelink and follow up the issues that have come up. One thing that came up at a previous inquiry around young carers is that a lot of them try to hide it and do not acknowledge that they are carers. It is exactly as Ms Dietz said: they are scared that people will come in and take over the family, so they do not identify that they are actually the carer.

Mrs Dietz—That is exactly what will happen. When we had that situation they were very defensive. They saw themselves in a role—and it was being valued up at the conference. At the conference they were being told, ‘You’re doing a wonderful job of looking after your mum and your brothers and sisters.’ Where are we coming from when we are doing that stuff? It is because we do not have to pay for it and we do not have to find someone to do it. And they are being neglected siblings; that is what is happening to them.

Miss Coombes—I just want to speak on behalf of my brother Robert. He is part of the DSQ and he is down in Ipswich. He is 51 years of age and he is in what I call an ‘outer house’. He shares with five other clients and they have no transport. Robert and another client are in wheelchairs, so they really need transport. If you are staying at home, as you know, you are confined. So then your personality changes; your whole nature changes. They are also on medication which affects their natures. So Robert really needs transportation. He gets a maxi taxi and it is ordered ahead of time. The carers say they have waited up to two or three hours before the maxi taxi comes. In one instance, the taxi did arrive but it was not a maxi taxi, so we had to wait longer. Out of the goodness of their hearts, my parents provided a second-hand maxi taxi for Robert, so we can now go down and visit him. Robert is about 40 kilometres away from us. Every time he has to go for an appointment, he has to pay for a maxi taxi and he has to wait. When the appointment is finished he is still waiting. So mum and dad go down once a week and pick him up and bring him home—and, as you can see, my mother has a disability. That gives Robert a chance to get out. Robert used to be able to get out and go for holidays, but he does not go for holidays anymore. He is confined and his holidays are cut out. He cannot be transported around without a cost to him. So DSQ have got a big issue with transport. We have had people up to our home to talk about transport. They talk about funding. They do not have enough funding. It costs too much money, because they have so many people in these outer houses who really do need transport. That is about all I can say.

Mr Coombes—In actual fact my last say is that there are too many bloody chiefs and not enough Indians. That is the trouble with DSQ.

Miss Coombes—Another thing with DSQ as well: if you are going to care for someone, you know as parents and as carers that they are used to one person handling them. If you have too many people handling your sibling they get confused. So we go down there this week and we will see Rhonda but we will not see Rhonda for another two months. Another thing that has happened just recently, Robert is in a wheelchair which were subsidised by MAAS. The tubing of the front wheel came off. We got a phone call. We are 40 kilometres away. It has got to be sent to MAAS to be fixed. It will be a week. Robert’s only means of getting around the house is a wheelchair. So then he goes in a chair which is like a big lounge chair with wheels on it. My father, along with my mother, goes 40 kilometres down the road, gets the wheelchair and fixes it. The alternative would have been a week away. But they cannot touch it because it is MAAS material. There have been a couple of occasions where we have had to go down there. What I am looking at is that DSQ does not seem to have someone there who can do maintenance work within that sector, a person to come up like my father, Darcy, or Tony or someone to go there and fix a minor little thing. That will also cost Robert as well, I believe, if I have got it right. So they are forking out all sorts of little costs everywhere.

Mrs Gerrard—Mine seems minor compared to the lady who just spoke. If you do not receive the mobility allowance because you are capable of catching a bus then you cannot get the taxi subsidy, which means that people who are on an intellectual disability who can catch a bus, if they want to go out at night there are no buses. We have trained two of our family members over a long time to use buses, so one of them turned up to Centrelink and said, ‘Yes, I can catch a bus.’ He had never caught a bus but he said he could catch a bus. We have been doing all this training. Now if he wants to go out to Down syndrome disco at night or he wants to go to a movie or a concert or something special for the disabled that is on at night, he cannot go out. It would cost him at least $20 to get there and $20 to get home, which is $40 for an outing, so he cannot do it unless he relies on parents to go out there at night to do it for him. Once we get involved doing it then that will be our cross to bear. At 70 there is no guarantee I am going to continue to drive. My husband cannot because he has got an eyesight problem. So we do not want to get started again on another sort of activity at night-time. That is a disadvantage to people who can catch a bus in the daytime but they cannot do anything at night because they cannot afford to do it on a disability pension. There are no buses at night here in Toowoomba, or on a Sunday. We now have Sunday trading but there are no buses on a Sunday.

CHAIR—I am just about to wind the session up. Is there anybody who has not spoken who feels now they want to speak having heard what other people have said and wanting to get something on the record?

Mr Coombes—I am Darcy Coombes. I am Carol’s dad. My boy, Robert, we were talking about transport at DSQ—the lady from Brisbane has probably heard of me—has an intellectual handicap. He could run around, he could ride a bloody horse. He started to fall over. He had to be operated on to make him walk better, so they took him off us, his mum and I. Twenty years ago, they operated on him. For 15 of them, he has never been out of the bloody chair, and I reckon: intellectual handicap, DSQ—same horse, different colour—owes that boy something. They took him off us legally, through the courts, and now he is dumped there. It is a bloody shame to see the position that that boy is in. Since the doctor hit him with the knife, he has never had a physio or a chiropractor, nothing, work on him. They just buggered him up. He is down there for anyone to see and look at his medical history. DSQ today was intellectual handicap. Thank you. But I hope it never happens to any of you people.

CHAIR—Thank you.

Miss Coombes—I have a comment to add to that. It is very, very important—through the experience that I have had as a sibling—for carers or any association to listen to the parents. They are the ones that do the hard yards. They are the ones that need the respect. Really, you are from the old school; ones coming up like us, or probably a bit younger, are ignoring what is right and what is wrong. We seem to be getting away with it a bit more, whereas, when you were at school, right was right, wrong was wrong. I think this has got to be looked at as well with carers, because a lot does get swept under the carpet when there is a problem.

Robert defied life. He lived. I think sometimes that, despite the miracles that can happen with doctors and nurses—they can perform amazing things and fix people’s deformity—sometimes it is best to leave things alone. Robert fought for a life, he cheated it and he lived. He walked, he talked to the best of his ability, and I think that was just the way it was planned for him to live out life. I think that intervening sometimes is not a good thing, so I do support my father in that. Yes, Robert probably would have eventually wound up in a wheelchair, but the thing is I think you are best to leave life to its own devices. Thank you.

CHAIR—Thank you. Thank you, everybody, for participating in the community forum section. It is very, very useful for us to get evidence based on people’s lived experiences and we very much appreciate it. I understand there are a few people who do want to put in a written submission following this; please do. We will accept any submissions from you if you want to send them into us. Thank you very much. That is the conclusion of this hearing. We will have another hearing in Canberra in the new year, but we have not set the date yet.

Committee adjourned at 3.38 pm