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**HOUSE OF
REPRESENTATIVES**

STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING
AND YOUTH

Reference: Better support for carers

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CANBERRA

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HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING AND YOUTH
Wednesday, 26 November 2008

Members: Ms Annette Ellis (*Chair*), Mrs Moylan (*Deputy Chair*), Mr Abbott, Ms Campbell, Ms Collins, Mrs Mirabella, Ms Livermore, Mr Morrison, Mr Raguse and Mr Trevor

Members in attendance: Ms Annette Ellis, Ms Campbell, Ms Collins

Terms of reference for the inquiry:

To inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

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**PARKER, Associate Professor Robert Michaelis, Chair, Board of Professional and Community
Relations, Royal Australian and New Zealand College of Psychiatrists 1**

STRAW, Ms Caralyn, Group Home Project, Mackay 9

Committee met at 10.07 am**NARKLE, Ms Tess Marilyn, Private capacity****PARKER, Associate Professor Robert Michaelis, Chair, Board of Professional and Community Relations, Royal Australian and New Zealand College of Psychiatrists***Evidence was taken via teleconference—*

CHAIR (Ms Annette Ellis)—I now declare open this public hearing into better support for carers. I welcome two of our witnesses by teleconference, Associate Professor Robert Parker and Tess Narkle. I will go through the formalities for the *Hansard* record and then we will get into a discussion with you both. The better support for carers inquiry was announced on 14 May 2008. Written submissions were called for, and 1,295 have been received to date. This is the 12th public hearing for the inquiry being conducted by the House of Representatives Standing Committee on Family, Community, Housing and Youth.

I now call representatives of the Royal Australian and New Zealand College of Psychiatrists, Associate Professor Robert Parker and Ms Tess Narkle. Although the committee does not require you to speak under oath, you should understand that these hearings are formal proceedings of the Commonwealth parliament and the giving of false or misleading evidence is a serious matter and may be regarded as a contempt of parliament. Do you have any comments on the capacity in which you appear?

Prof. Parker—As you know, I am appearing as Chair of the Board of Professional and Community Relations for the Royal Australian and New Zealand College of Psychiatrists. I might just quickly add that Tess has very kindly come on my invitation. She does not really have any connection with the college but she has very kindly agreed to help the committee today on her part as a carer.

CHAIR—Tess, could you just repeat the capacity in which you are appearing here today?

Ms Narkle—I am appearing as a carer of someone with a mental illness.

CHAIR—Thank you very much. I will introduce the people here at the other end. It is a sitting day here in Canberra so I hope you will forgive us if some members tend to come and go a bit, because that is what happens in this place when the parliament is sitting. I am Annette Ellis, the member for Canberra and the chair of this committee. I will just ask my two colleagues who are here to introduce themselves to you.

Ms CAMPBELL—Hi, Rob and Tess. I am Jodie Campbell, the member for Bass, in Northern Tasmania. Good morning and welcome.

Ms COLLINS—This is Julie Collins. I am the federal member for Franklin, in southern Tasmania. Good morning.

CHAIR—Again, Robert and Tess, thank you both for being there. Robert, would you or Tess like to make any opening remarks to the committee before we get into a general discussion? Please do go ahead if that is the case.

Prof. Parker—I just want to start by saying we put our submission in, and I was an author of that submission. I had a chat to Tess the other day and I think she has got some very good information to give the committee that basically backs up what we put in the submission—but also on her own behalf. I think it is probably more valuable for Tess to tell you about her experiences as a carer of an Indigenous person with severe mental illness than for me to talk about our submission.

CHAIR—Okay. Robert, we might come back to you in a moment with some questions we want to ask you. Tess, we very much welcome the contribution you can make from your perspective, so please just go ahead and tell us your story.

Ms Narkle—My position is that I am a registered Aboriginal health worker in the NT and I have worked with people with mental illnesses. It has been my job for the last 15 years. It was not until this happened in my family—it is my son; five years ago he was diagnosed with a mental illness—that I fully understood the hardships that families go through trying to get support and outside help for them while they are full-time working parents.

CHAIR—Do you want to go further and just give us some examples of what you have been going through?

Ms Narkle—With my work, I have taken off nearly 12 months long service leave plus all my sick leave and whatever rec leave I had to care for my son and take him in to see the psychiatrist and other professionals. It has been a very hard, long struggle because with his illness he does not like to be left alone, so I have more or less had to be with him most of the time. Being a one-income family, that has been very hard, and it has impacted on Sean's younger brother and sister, who also have worked to try to support their older brother. But in the long run it has just been a very hard struggle, and I have come close to suffering from chronic depression myself, just trying to cope with it by myself, feeling so alone and isolated.

CHAIR—Tess, can I ask you a couple of general questions. Does your family live within the Darwin district or do you live outside of Darwin?

Ms Narkle—We live within the Darwin district.

CHAIR—So you are within the Darwin area.

Ms Narkle—Yes, 15 minutes from Darwin centre.

CHAIR—Because you are an Aboriginal health worker professionally, you have two aspects to this, don't you? One of them is your professional experience that you will have already seen happening with other cases and then of course there is your own personal experience. Is that fair to say?

Ms Narkle—Yes, that is fair to say. And it is a whole new experience when it is someone in your own family.

CHAIR—How old is your son?

Ms Narkle—He is 30 years of age and this happened when he was about 25.

CHAIR—The point that we are really interested in talking to you both about is the difference, if any, that faces Indigenous people or communities or families as opposed to non-Indigenous people who find themselves facing a caring role and the impact that has on their family. We would like to know whether there is any difference between the frustrations and the pressures that you face as against non-Indigenous people. Do either of you have a comment to make on whether there are added concerns or problems because of the family background or do you think it is the same for everybody? We have not had very much feedback in relation to the Indigenous community and we are very keen to get that perspective.

Ms Narkle—I believe that Indigenous people have always had it very hard—harder than the normal population. With something like mental illness, there are always a lot of doors blocked. We find that it is a bit harder to receive or come in contact with the help, I suppose, that Indigenous people need as opposed to non-Indigenous people.

CHAIR—Tess, have you been able to access Indigenous-specific mental health services?

Ms Narkle—We do have one in Darwin but we found it very hard—we have not accessed them because at the time I believed my son's condition was very severe and probably needed to be treated within the medical stream through the Royal Darwin Hospital.

CHAIR—Within the mainstream?

Ms Narkle—Yes, in the mainstream.

CHAIR—Robert, do you have any comment you want to make at this point about whether or not we need Indigenous-specific services and whether or not we have got them?

Prof. Parker—There are a whole range of issues that obviously impact on the experience of an Indigenous person in Australia suffering from mental illness at the moment. There is the whole issue of the resilience of community and there are a number of issues about communities and support of those communities. Often Aboriginal carers themselves have got a significant burden of physical illness, if not mental illness, and quite often the ability to access services is significantly restricted.

There has been some very good, thoughtful work done on this recently in the book by Michael Dillon and Neil Westbury called *Beyond Humbug*, which looks at the failure of government with respect to Indigenous Australia. They mention that, particularly in remote areas, there is a failure of governance. There are just not government services. So, if someone becomes unwell, the family are often very exposed to the effects of the illness and are expected to cope.

In urban communities Aboriginal people often live in the more marginalised and disadvantaged areas, again where there are significant issues about access to appropriate services. I am very aware that one of my Aboriginal friends from Sydney recently had significant issues accessing appropriate services for her daughter, who was very unwell. She was very dissatisfied. This woman is a leading advocate for mental health in Australia and was very frustrated and angry about her experience. Certainly there are issues.

There are all sorts of issues about what constitutes best care. Ideally, I suppose, it would be primary care, where there is a well-functioning Aboriginal community run health centre with stable staff and Aboriginal health workers who link in with the mental health service to provide the best, coordinated care for someone with severe mental illness. That would involve working with their family. It would be the role of Aboriginal mental health workers to coordinate that and to provide a level of cultural security for the person and their family in dealing with services.

The current level of funding and actual provision of services means that it is a fairly rare event. Obviously for Aboriginal families living in remote and rural areas—the Territory's Aboriginal population is primarily a remote and rural population—access to services is even more restricted. So, again, with people having illness, the ability to access services is fairly limited. That being said, in the Territory we now do have a rural mental health team staffed by a couple of very experienced psychiatrists and nurses and I think they do their best to coordinate with the rural clinics to provide the best care for Aboriginal people suffering mental illness in communities. There are other issues too.

I have written a couple of chapters for the new COAG Aboriginal and Torres Strait Islander mental health textbook. I am more than happy to send them to Allison if the committee would like to see them.

CHAIR—Yes, thank you.

Prof. Parker—They outline a lot of background factors and family factors with respect to access to services. Tess might have some comments on this. They are often stories about mental illness that operate within the Aboriginal community for affected people. The Aboriginal communities are fairly close here, so if someone becomes ill it is often fairly public knowledge from a range of families and communities. Quite often there are other myths or there are experiences that other families have gone through that may or may not be quite correct in terms of the information they have got on diagnosis or the experience of that person, which then may actually impact on rumours surrounding the person who has got mental illness at the moment and their access to care and the way that people treatment them. All those issues work as well.

CHAIR—Robert, thank you for that. Yes, please, we will have those chapters you mentioned.

Prof. Parker—I will send them to Allison.

CHAIR—That would be a great help.

Prof. Parker—They are a draft at the moment, but I do not think they will be changed that much.

CHAIR—We know from speaking to a raft of people around the country that, in general terms, particularly in the mental health area, people who are caring for someone with a mental health issue have issues over and above or different, fairly unique, in comparison to caring roles in other settings. The relationship between the carer, the patient or cared for person and the professional is one angle. There is the access to respite, so that the carer and the family can actually have a break and so that the cared for person can have a break as well. We understand in general terms that that is already very difficult for many people around the country, so we can only assume that in Indigenous-specific cases it is even more difficult, it is even more hard, because of the circumstances of geography, culture and access to services. Are we making any incorrect assumptions there are or are we on the right track when we make those assumptions?

Ms Narkle—Yes, I would say you are on the right track there.

CHAIR—Tess, has your family had any access to respite at all?

Ms Narkle—Just lately I am getting respite help, and this is the first time that has happened for five years. It has been a long battle to get that.

CHAIR—What sort of help are you receiving?

Ms Narkle—My son is staying at a respite place at the moment. They usually take them for up to about four weeks just to stabilise them a bit and help them so that they are able to care for themselves and be more independent.

CHAIR—This is the first time you have had that assistance in five years; is that what you said?

Ms Narkle—Yes, this is the first time.

Ms COLLINS—Excuse me if I sound a bit ignorant, but I wonder if you could tell us what the cultural issues would be. We have had a lot of representations, particularly from the college of psychiatry, about the need for the carer to know about the care situation required for the person being cared for and some of the barriers and the legal issues around that. Are there any cultural issues that we need to be aware of or that need to be put on the record that might be different that we do not know about? For instance, Tess, I am talking about the case where the parent needs to know about the care regime for the mentally ill child and the legal issues around that. We have had representations and I guess I am wondering whether there are any cultural issues around that that we need to be aware of.

Ms Narkle—I am not sure. There could be. I know, on my behalf, I needed to be fully involved with my son's care so that we were getting the same story from the doctor and other carers or other people that were offering medical care, otherwise I found that he would come out and tell me one side to something and not tell me everything that the doctor had said or something like that. Sometimes this was detrimental to his health. For my peace of mind I found I had to be informed of everything that was going on. My son realised that that was the best way to go.

Prof. Parker—Tess, did you feel that you were able to do that satisfactorily? You were able to approach people and get the information you required?

Ms Narkle—Yes, I have been, because I have been very persistent with it. Being an Aboriginal health worker, I have taken other clients in for their appointments. I could see, from their parents' perspective, the story they were not getting. I found it is very important for Indigenous people—relatives, family, especially the main carers—that they knew everything that was going on.

CHAIR—Can I just say that your family is obviously benefiting, Tess, by the fact that you have the professional role that you have and that you have a bit of knowledge that other families may not have in relation to how these things work.

Ms Narkle—In having that knowledge I found it very hard also—I am still finding out stuff today. In my role as a health worker I try to help other families also.

CHAIR—Robert, in the submission to the inquiry from Carers New South Wales there was a suggestion that there is a need for a national Aboriginal and Islander carer framework. What would you suggest or believe would be the essential elements of such a framework? Given the cultural and geographical diversity of other Indigenous populations, what challenges would you understand or guess would be associated with adopting a national approach like that, should we go down that path? Do you have a view on that?

Prof. Parker—It is actually quite a complex issue. In the Territory we are probably slightly ahead of other jurisdictions in that the mental health legislation actually mandates giving information to carers where people are under the act. There is also a carers act in the Territory and our public health services have obligations under that act with respect to carers. So a change in the legislative environment is certainly one issue that could be looked at by the Commonwealth. I understand that in the mid-nineties, for example, the UK parliament passed legislation with respect to carers and certain standards. That is now filtering down into the Australian legislative environment. I suspect some form of legislation to look at the role of carers would be an important issue that would underpin any carers network.

I think also cultural safety has a role to play. Cultural safety is mentioned in one of the chapters in the book. It is an essential component of dealing with an Aboriginal person with mental illness. That involves Aboriginal mental health workers playing a role and including the family and the location so that the person and their family feel engaged within the area. A carers network could involve local services appreciating and promoting cultural safety in the care of any Aboriginal person who had severe mental illness. I think that would automatically lead to an improved role for carers.

There needs to be an improved primary care focus so that there is better liaison between the local Aboriginal controlled health services and the mainstream. I think there are often significant issues of linkage between the two and the potential care both for person and their family in that situation. So there needs to be an enhanced awareness of the primary care focus for Aboriginal people with mental illness.

Some of the issues are fairly universal and relate to funding, such as the provision of services. I mentioned at the beginning that a lot of Aboriginal people are in remote areas. Their access to government services is very restricted. They are also often living in marginalised areas. Perhaps there could be specific funding to enhance those areas of need and provide an information base and some sort of linkage between carers. We have organisations such as ARAFMI that try and link the families of people with severe mental illness and empower those families to care for relatives. Maybe there could be some sort of linkage set up between Aboriginal people around Australia, such as some sort of information net or web based chat room, where people could get together and just talk about the issues and the problems they are having, to empower themselves to deal with organisations.

CHAIR—Linking into what you just said then, Robert, the other comment I would like to bring up would be the number of people in general Australia who do not see themselves as carers. I imagine that in our Indigenous community, given the family based nature of it, there will be many cases where people do not actually identify themselves in the formal sense as a carer—that is, in the sense that we are speaking of here. Is that the case? You mentioned that linkage situation. For argument's sake, would NACCHO be a possibility for assisting in building those linkages and formalising them through the connections that they already have?

Prof. Parker—I think NACCHO have a particular role. I am very happy for NACCHO to be given further support to do whatever. I am very impressed with the organisation. Again, this is one of the chapters of the book of the book that I am sending down to you. Aboriginal culture in its traditional form was very well set up to deal with people in a care situation. I spent three years in the Tiwi Islands doing Aboriginal art and craft before I went into medicine and I was very aware of how people were looked after generally by communities. A range of people were allocated to look after someone—both children and adults with disabilities. So not just one person was burdened with it. I think Aboriginal culture probably could have taught the rest of Australia about caring before it was decimated and significantly disadvantaged by all the current issues that it has.

I think a lot of those networks still tend to happen. There are still aunties and uncles who can help. The problem is that, as was pointed out, with the way the culture is at the moment a lot of the aunties and uncles have severe physical problems themselves and are often quite restricted by a whole lot of other life circumstances in the caring role. You have people such as Tess who obviously, living in the urban area, are not able to draw on the traditional family supports that may have been available 50 or 60 years ago and are very isolated and very stuck in their ability to access services. Tess has described the effect on her, with having to take months off work and going to the limit of illness within herself to try and deal with her son's illness. I think that is more the predicament of Aboriginal people these days than the sorts of things I was observing 20 or 30 years ago on the Tiwi Islands, which is fairly sad. I think it was actually a very good caring environment. I think it is far less so, and I think a lot of it has to do, as Dillon and Westbury point out in their book, with the withdrawal of government services. Thirty years ago, there was stable government involvement in Aboriginal communities and they were able to set up and provide services. There has been a significant reduction, and I think it has led to disadvantaged people being even more disadvantaged in establishing those sorts of issues.

CHAIR—Thank you. They are fantastic points you have just made, and I thank you for that. Tess, I will just ask you something quickly, because we are coming towards the end of our time,

sadly. You mentioned that your son Sean has a younger brother and a younger sister. How old are they?

Ms Narkle—Twenty-four and 22.

CHAIR—Are they all still living at home?

Ms Narkle—Sean, who is 30, and the younger sister, who is 22, are at home. The second son has just gone interstate to work with the mines.

CHAIR—I was only asking that because, although you are obviously the major carer, the family inevitably becomes involved as well one way or the other. I am just wondering if you want to say anything briefly on the impact of this whole caring situation in relation to the siblings.

Ms Narkle—As children of today, I suppose, they sometimes believe that it is not their role to look after the other child or take him on to watch him while I need to go shopping or something. We have debated, argued and discussed this many times with my son and daughter. When they see that I am really at breaking point, they will help. They have seen their brother have a psychotic episode at home and have fits, and then they have come around to provide empathy, and they help out then. I am from WA—Perth—and I have been in the Territory for 28 years, so I do not have any of my immediate family around in Darwin. That probably has a lot to do with the isolation from family support.

CHAIR—Sadly, we have to draw this to a close. We find when we are talking to people like you two that we could go on forever. I want to formally thank you both. Robert, is there anything that you want to say in quick conclusion before we formally end?

Prof. Parker—Not really. I think Tess has presented most of the issues, and I thank her very much again for assisting us today. It was very kind of her.

CHAIR—Thank you. We are very grateful to both of you for spending the time with us this morning, and we thank you sincerely. Thank you both very, very much. We appreciate your contribution.

Prof. Parker—Thanks very much.

CHAIR—All the very best, Tess.

Ms Narkle—Thank you very much.

[10.40 am]

LA FONTAINE, Ms Suzanne, Carers Queensland, Mackay Office

DOWNING, Ms Lyn, Group Home Project, Mackay

STRAW, Ms Caralyn, Group Home Project, Mackay

Evidence was taken via teleconference—

CHAIR—Good morning. I want to formally welcome you and declare open this part of our public hearing today for our inquiry into better support for carers. I welcome representatives from the Mackay group home project. This is the 12th public hearing for the inquiry being conducted by the House of Representatives Standing Committee on Family, Community, Housing and Youth. The inquiry was announced in May 2008. We have received just over 1,295 submissions to date. Although the committee does not require you to speak under oath, you should understand that these hearings are formal proceedings of the Commonwealth parliament and giving false or misleading evidence is a serious matter and may be regarded as a contempt of parliament. Do you have any comments on the capacity in which you appear?

Ms Straw—I am coordinating the project that we are endeavouring to put together.

Ms Downing—I am also part of coordinating the project for the house. We would also like to apologise that Liz Jacks could not get here today.

CHAIR—No problem.

Ms La Fontaine—I am the regional carer services officer here in Mackay and I am here to support Caralyn and Lyn in their endeavours.

CHAIR—Thank you. I will just draw you a mind picture here. We are sitting in a large committee room in Parliament House with a bit of an echo. We have Hansard here and we have committee staff here, so please do not be shy about speaking up; it might just make it a bit easier for us to hear you clearly. This is Annette Ellis, chair of the committee, speaking, and I will just introduce my two colleagues who are with me here this morning.

Ms CAMPBELL—Good morning. I am Jodie Campbell. I am the member for Bass in Northern Tasmania.

Ms COLLINS—It is Julie Collins here, and I am the federal member for Franklin, in southern Tasmania.

CHAIR—Terrific. Thank you very much for being with us and thank you for your submission, which we also have with us. Before we get into a general discussion with you, do any of you want to make just a brief opening comment at this stage, additional to your submission?

Ms Downing—We are speaking from our offices, so we are only on speakerphone, so if it is not clear just let us know. The project for our house has changed slightly from the submission, only in that we are a little bit further along the track and will hopefully be able to put in our submission to Disability Services Queensland in the not-too-distant future.

CHAIR—Okay. Can you just bring us up to date on how far you have got, because you are frontier pushers—

Ms Downing—Thank you; we try!

CHAIR—that we admire. We read your submission, and that was done back in June, so if you would like to just give us a very quick update on how far you have advanced since then.

Ms Downing—All right. We have come to a point where we have had quite a few meetings and worked out, with help from different organisations within Mackay, how to prepare our submission, and everyone has been extremely helpful. We are at the point now where we have the facility available and we have got costings. The last little bit that we are working on at the moment is a risk assessment.

The proposal that we initially put in was for high-functioning but high-support young ladies. The youngest is 18 and the oldest at this stage would be around 25. The whole idea of our submission is for the parents and young adults to have as much input into the running of the household as possible. The idea of having five young women together is that we give them friends. They can go out as a group. They have support.

What started this for me was that Caralyn's and my children are friends and we work together to support each other. For example, one will drop them off at the movies and the other will pick them up. I remember walking into the movies and seeing these three young disabled people walk out laughing and talking. They did not even see that I was there. It was just like three other teenagers walking out of the movies. It warmed my heart that these kids could have the same sort of thing as anybody else.

That is why we looked at having five people in a house. Like everyone else, you are going to have people who share a house who do not get along. As parents, Caralyn I could let our girls who are friends share, but if there are five people, if you have a disagreement with somebody you have somebody there who can support you or be a friend to you. You get that with people with a disability, as you do with any teenager or anyone else. There are going to be times when people do not get along. This gives us a broader scope so that people can have that company and support.

CHAIR—Lyn and Caralyn, you are both parents of young people involved.

Ms Downing—That is right.

CHAIR—What about you, Suzanne?

Ms LaFontaine—I am the regional carer services officer for Carers Queensland.

CHAIR—Okay, thank you. Lyn or Caralyn, can you just tell us for the sake of the record why you are doing this. You are both carers. Why do you believe you want to do this?

Ms Straw—I put together a brief summary of why and where we are up to. Could I just read through that?

CHAIR—Sure.

Ms Straw—After discussing the possibility for our girls to experience independent living, as most young adults do, my friend Lyn and I went to work sorting out how we could make this dream a reality for our girls. We knew of others who might be interested and spread the word. On 14 May this year we had our first meeting with five interested tenants or representatives thereof. Research was done into the Brisbane based Allamanda Autistic Adult Accommodation Association. With their accommodation set-up, individual funding of the tenants was required. All of our interested parties had been unsuccessful in this area of support.

Our mission, I suppose you could say, is to cover these individuals—the middle-of-the-road people. They have enough of a disability to need high support and do not fit into the community without consistent, help, support and therefore supervision, but they are not disabled enough to be eligible for funding and inclusion in the available specialised accommodation that is in town.

Our findings are that these families work hard enough to survive this situation by doing all the extra things needed. This may mean starting up a business or doing extra work through their employment and doing all the running around needed to keep these young adults members of the community, therefore putting stress on all other areas of their lives. Friendships, as well as family relationships, suffer. Sheer paperwork can be a major part of a carer's day and add costs, because you often need recent medical proof of the disability, as well as other paperwork that has to be rounded up.

My main concern is: after all this work that we have done, will DSQ, who we are putting the proposal to, even have the access to funding that we are proposing? The work we have conducted so far consists of weekly budgets for the tenants, tenant agreements with the landlords, risk assessment, house rules and rosters, feedback forms and a compatibility procedure, not to mention the proposal to DSQ, which comes to a grand total of \$244,270 annually, with an initial total of \$315,270. Does that answer the question?

CHAIR—Yes, it does, because it brings us up to date with where you are up to. Can you just explain where you are going to find the house and how you are going to locate the property.

Ms Downing—We actually have a house. My husband and I have made a suitable property available, which has five bedrooms plus an area where we can accommodate a 24/7 carer. It is centrally located. We have also applied to DSQ for a vehicle so that these girls can be transported. Some work part time at different places with support from employment agencies for disability and others work full time for the Endeavour Foundation, and the girls need to be transported, so a vehicle is part of the application. The particular house that we have, which belongs to my husband and me—or our company—has been made available at a nominal rent.

Ms CAMPBELL—I have a couple of queries. The first one follows on from when you were saying that you were unsuccessful when you applied for funding. Could you explain to me why you were unsuccessful in that funding round. Also, in relation to the submission that you put in, Caralyn, you say that there should be more packages for people with disabilities. Could you comment on what packages you think should be available.

Ms Straw—Yes, I can. I have recently been unsuccessful with a funding package and with a postschool package that would enable Tammy to further her studies and possibly live in accommodation that we are putting together. We do not get given a reason other than that there were 11 applications put in. Six were successful, because that is how much money they had available, and four others were unsuccessful. Simply, the ones that were successful had higher needs, which is why I mentioned that borderline that we sit on. We have not got wheelchairs or obvious things that cost us money for us to be considered to have a high need for these packages, but we do have consistent, 24/7 concerns for our young adults that are a drain on us both emotionally and monetarily. That is what I mean by ‘more packages’. Why isn’t the funding covering the number of people who are applying for the packages?

Ms Downing—We have not actually put our submission to DSQ as yet—neither Caralyn nor I. I have had two submissions to DSQ for postschool, and Brianna has been unsuccessful with both of those for the same reasons Caralyn stated. We are in the final throes of presenting our submission to DSQ, so we have not actually been knocked back yet, but as you can see we carry a bit of baggage in the community that we will be.

Ms Straw—Also, this is why we are putting the proposals forward to DSQ. With this proposal, they would be covering five prospective applicants. Otherwise, these five people are going to keep applying and keep getting knocked back, maybe—that is how we feel—and therefore give up.

Ms Downing—It is also the case that, if Disability Services Queensland actually operate as an efficient business, they can cater for five families for the same cost, or less cost with our support, as one family with 24/7 care.

CHAIR—We are talking about young female adults with intellectual disability, are we not?

Ms Downing—There are variations. My daughter Brianna is autistic and has an intellectual disability. Brianna also has obsessive-compulsive disorder and a few other things thrown in that generally go along with it.

Ms Straw—My daughter has Down syndrome and intellectual impairment. Overall, most of the people we are looking at have intellectual disabilities, not physical.

CHAIR—What legal or liability implications are there, if any, in your view, when setting up a home of this type? If there are any, how are you progressing that side of it?

Ms Downing—We have not got to the stage where we have looked at insurance, but we are well aware that we need public liability insurance. As far as the carers go, they will be provided by a support group and they will be covered under their own insurance. That is one aspect of it

that we have not pursued. But, being associated with a high-profile in industry like the coal industry up here, we are well aware of the cost that is involved in covering that insurance.

CHAIR—I suppose this is an obvious question, in a sense. Is there any local organisation already set up in one form or another under which you could possibly apply for this to sit, even though you could retain some independence? Or is it better for you to go down the path you are pursuing?

Ms Downing—We have tried numerous avenues. The plan that we have is unique, as I said, in making these girls peers and friends, not just strangers. If you take a house currently with Disability Services Queensland—

Ms Straw—You have to have funding. Without funding there is nowhere for our children to go, because we have to pay for 24/7 support.

Ms COLLINS—Could you just put on the record for us, if your children do not go into the group home, what sort of support you are eligible for and/or receiving currently. How would that change in the group home?

Ms Straw—Apart from emergency respite and support from Carers Queensland and the like, none.

Ms COLLINS—Are you eligible for any that you have not applied for?

Ms Downing—We get carers allowance and the girls get their disability pension, which is a nominal amount. I am not aware of whether anyone has had much involvement with children with disabilities, but my daughter can go through a bottle of shampoo and conditioner in one day and God knows what else in a week, so the cost involved in having a child like this in repairs, maintenance and whatever you can think of is nowhere near what you are given in a carer's allowance.

Ms Straw—We do not get the pension.

Ms LaFontaine—We do a lot of advocacy for carers in the region. It is part of my position as the CSO. A lot of carers are in this position. This is not an isolated group. A lot of people contact me on a weekly basis saying that they are not eligible for DSQ funding, that the funding is too confined to people who have very severe disabilities and cuts out those people who also need assistance but find that there is not sufficient funding to go around to support them.

Also, I understand that the government was gearing towards supporting people with disabilities in the home, but because services are so geared towards this it is not flexible about carers who that does not work for. It does not work for all carers. It is not the ideal situation for all family carers that the recipient remains in the home with them.

Ms Straw—May I add on that topic that as a carer, as a parent, we are lifetime carers in this regard. We have not got the choice of the children leaving home and living a life of their own. We are employed to look after them for the rest of their life if we cannot find another avenue. This can be very wearing and we have not chosen this form of employment; it has chosen us. If

we went out to get a job and became a carer we still have the option to leave and go and find another job. We often wake up with that feeling—not me personally, but my husband has often said to me, ‘They are going to live with us forever.’ Where are they going to go? What are they going to do? They cannot even speak coherently to people so that they can understand what they need.

Ms La Fontaine—I have a number of people caring for young adolescents with intellectual impairment and there is actually nothing provided for them in Mackay after they finish at the special education unit. There is no life-skill development. There is no funding for that available and I have seen mothers distraught, saying, ‘What else can I do? My daughter sits and watches TV all day. There is nothing else for her.’

CHAIR—I want to thank you for the frankness of that discussion. As you obviously understand, this inquiry is all about the carers and the impact that the caring role has on their life, their family, their wellbeing, their finances or any other part of their lives. What you have basically just described is something that we have heard a lot. What you are offering us by being with us today and by submitting to the inquiry is evidence of the extent to which you are willing to put effort into trying to establish independent lives for your young people. I have to say personally that I admire the fact that you are trying to do that, obviously against enormous difficulties—and my colleagues here are nodding enthusiastically to that comment. We are going to have to draw this to a conclusion, but I want to ask if any of you have any final comment that you would like to make. If you have anything additional to say, please feel free to.

Ms Downing—Thank you for the compliments on the effort that we have put in. We are doing this—it is a typical human trait—out of necessity. In my situation, with my daughter the way she is, we have stuck together as a family unit but do not know how long we could go on that way. Necessity is the mother of invention. This is where we come to for our families to survive and to be able to have some normality. I have a 12-year-old son who misses out. I am at the stage now where Brianna is nearly 20 and it is time that my son was given some attention. We are doing this not only for our girls; we are doing it for our families and hopefully for the community in the long run, because if we get this one through then maybe we will be able to help many more families. If this one comes through we will give them the information and there will be a lot of other families that will gain out of it.

Ms Straw—May I add that the family unit as we are experiencing it is a rarity. There are a lot of carers out there that are doing it by themselves because their families have fallen apart. We can speak from experience that long-term friendships have come to an end as well. I would also like to put on record that my husband and I have noticed that pensions are a set amount throughout Australia but living costs are not. Different areas are more costly to live in. Couldn’t this be considered as it is with our tax benefits? Once our children are not children anymore we do not receive that tax benefit, but they are still living with us. Yes, we can take some of their pension to help cover that, but meanwhile living costs are higher here than what they are in metropolitan areas.

CHAIR—Thank you, Caralyn. Suzanne, do you want to say anything to finish off?

Ms La Fontaine—I guess it is actually only the government departments such as DSQ that know whether the issue is not enough funding or about how that funding is actually distributed. I

guess that is a question that only you could answer. Whichever way it is, there is definitely insufficient finding here for people such as Lyn and Caralyn, who are caring for children with disabilities. The gap is not only there; it is also with people who are over 25 and under 65 who have acquired brain injury. There is very little ongoing rehabilitation available for them and their carers are also struggling. Thank you.

CHAIR—We thank the three of you for your attendance here today, and our very best to your colleagues who are not with you this morning. Good luck with your ongoing work. We very much appreciate the contribution you have made to our inquiry. Thank you. Is it the wish of the committee to authorise publication, including publication on the parliamentary database, of the transcript of the evidence given before it at public hearing this day? There being no objection, it is so ordered.

Committee adjourned at 11.07 am