LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, COMMUNITY AND SOCIAL SERVICES

(Reference: Respite care services)

Members:

MR S DOSZPOT (The Chair)
MS A BRESNAN (The Deputy Chair)
MS M PORTER

TRANSCRIPT OF EVIDENCE

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Secretary to the committee:
Ms G Concannon (Ph: 6205 0129)

By authority of the Legislative Assembly for the Australian Capital Territory

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WITNESSES

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Amended 21 January 2009

The committee met at 10.32 am.

BIGBY, PROFESSOR CHRISTINE, Director, Postgraduate Program, School of Social Work and Social Policy, La Trobe University

THE ACTING CHAIR (Ms Bresnan): Professor Bigby, thank you for appearing today to address the Standing Committee on Health, Community and Social Services inquiry into respite care services. I draw your attention to the privilege statement, which is on the table in front of you, just to make sure you are aware of that and have read it. Before we go to questions I believe you have a presentation you wanted to give to the committee. So we go to you, Christine.

Prof Bigby: The reason I was asked to talk today, I think, was to look at issues around a particular group of people that use respite care, which is older carers, primarily older parent carers of people with a lifelong disability. They are one of the subgroups that use respite care, that have high users and that have been given significant priority in policy issues over the last couple of years. I guess I am speaking from a whole range of research that I have done over the last few years, which has looked at issues to do with older carers and people with a lifelong disability, the policy context of that, their use of respite care, the types of programs that are useful and the types that are not. I can talk to this, but it might be better if you interrupt me and ask questions rather than me just talking.

THE ACTING CHAIR: We will see how we go.

Prof Bigby: I think it is important, first of all, to see that respite care fits within the broader policy context of disability policy, because it is about services for people with disabilities and their families. The broader disability context at the moment is clearly focused on rights, choice, participation and independence, as far as possible, for the person with the disability and the support to provide that independence. Service delivery is moving clearly in terms of individualised, flexible support that is directed as much as possible by the person with a disability, together with the significant people in their lives, which moves away from the standardised types of fixed programs that have existed in the past.

The national disability agreement talks about enhanced quality of life but also participation of people with disabilities and their carers in the community. So it is not just about people surviving; it is about people having a quality of life and being supported to participate in the community. Older carers have been singled out in the national disability agreement as one of the priorities for funding and support.

Bearing all of that in mind I think it is really important that respite programs take into account dual outcomes so that there are outcomes not only for the carer or the family, in the bigger family context, but also for the person with a disability—so they are getting outcomes from the respite program as well. I guess that is the significance of this group of people who are living with older carers and how respite might be used to support them.

As I am sure you are aware, there has been a whole range of state and federally funded initiatives over the last few years to focus on the issues of older carers and people with disabilities that they are supporting. They have framed the problem very much in terms of the need for respite care full stop and have ignored the complexity of those people's family situations and their future needs: the care has got to stop sooner or later and there has to be planning around future needs. As each program comes along it has just been added to what is there, so you have got this amazing fragmentation now, particularly with refunded programs. Lots of little bits and pieces have just been added onto the other.

The underlying issues, I think, in terms of the context of older carers is that there is a growing number of older parent carers of people with disabilities. These figures are way out of date, but they are the latest good figures there are from the ABS. It is clear that this population is increasing. That is historic, because now it is fairly certain that most children with an intellectual disability or with some other form of disability are likely to outlive their parents, whereas in the past people with disabilities had a much shortened life expectancy. People's life expectancy is increasing and the chances of outliving their parents are much higher. There is also the demographic bulge of people, the postwar baby boom generation, where the parents are going to be reaching old age and their children are going to be moving into middle age. So there is going to be this increasing number of people.

You have got parents being outlived by their children. The housing and support patterns of the past have meant that some people have gone to institutions, but they have always been a minority. The majority of people have always stayed at home with their families. You have got a whole generation of people with disabilities that are living in the family home and are continuing to do that as they are ageing and as their parents are getting really frail aged.

We have had policies in place, as you are well aware, where people should be able to live a much more normalised pattern of life and therefore should be able to leave home when they are young adults, but there has been almost no growth in accommodation support to allow people to make that transition. We have created this problem of people living with older parents because we have not done good policy implementation at earlier parts of the life course. All of that is within the context of continuing unmet need for alternative accommodation and housing support. Again, these figures are out of date, but they are the best that are available.

THE ACTING CHAIR: I am sorry to interrupt you, but do you think—you said there has not been growth in accommodation support—that respite has become a de facto program in a way to address that gap, because those are the only programs that are being funded?

Prof Bigby: In a sense, for that group of families that is all that has been available—bits and pieces of family support and, increasingly, bits and pieces of respite. The problem of older carers of people with disabilities has been identified and it has been responded to in terms of "Let's give them some respite" rather than "Let's think about what the underlying issue is, which is the need for people to make the transition from parental care and find alternative supported accommodation or go and live in group homes or whatever suits them." The solution has been very much a bandaid solution in terms of bits and pieces of respite care. Also, in the long term you need to help people to leave home if they are going to live a more normalised life. If you do not do that you are going to have a continuing issue about older carers of people with disabilities.

This group of parents have made a lifelong commitment to family care. That is what they chose to do. When their children were young they could either take them home and look after them with very little support or leave them in an institution. These parents who are now ageing chose to take their child home. In terms of equity, they have had almost no services from the system compared with the people who chose to use institutions. The research shows that those people want to care for as long as they are able to. They are not choosing to give up caring. They want to choose. They want to continue to care for as long as they are physically able to do that and are alive. Some of them want support to enable them to do that.

The adults with disabilities who are living with them also want to stay at home for as long as possible. In a sense, they are quite happy with the situation as it is at the moment. But, unlike other caring situations, for this group of people, the end of caring is going to happen when the parent dies. Normally with older carers you have got siblings who look after their parents. The caring stops when the person being cared for dies. But in this situation it is when the carer dies, which means you know there is going to be a crisis in future. There is going to be an end to caring by that parent, but the caring is going to need to continue.

MS PORTER: Can I ask a question about the institutionalisation of some of these people back when their parents made the decision. These institutions would not still be functioning, would they?

Prof Bigby: It depends where you are. I am not sure about the ACT. In Victoria, we have closed all but one of those institutions. In New South Wales, there are still a significant number of those institutions there today.

MS PORTER: What happened to those—

Prof Bigby: What happened to the people in the institutions?

MS PORTER: Yes, that is right. We do not have any institutions in the ACT, so regardless of what decision these people may have made earlier on, if they are living in the ACT now, they must be with their parents or siblings.

Prof Bigby: Or in supported accommodation.

MS PORTER: Or in supported accommodation.

Prof Bigby: So the people that moved to institutions in Victoria, and those institutions have been closed, have moved out to supported accommodation. In a sense, if you look in terms of equity, the people that chose to put their child in an institution now have not got that lifelong caring responsibility and they have now got alternative, relatively good accommodation; whereas the ones who chose to stay at home have not been able to access supported accommodation because there has not been growth. It is almost like the institutional beds having been replaced with community beds, and there is no extra.

Part of this argument is that there is going to be, for people living with older carers, a time, and you know it is going to happen, when the parents are going to die or become incapacitated, when that transition from parental care is going to have to happen. Respite care and respite programs can be used as a way of avoiding that future crisis, of avoiding having an unplanned transition to inappropriate accommodation. If you use respite programs to begin to think about preparation and planning for the future, a way of thinking about how to retain family support and family capital, how to replace the parent roles—and parent roles are many; so parent roles about primary care but also about advocacy—and in terms of the adults, they can be used in order to develop much greater independence and to widen the adult social network. So if you are using respite as a precursor to leaving home, you can use it as a way for people to begin to let go and separate from their parents, to develop their own networks and to begin to use some of the skills that they probably had but have not been able to use.

That is where the dual role of respite comes in for this group. You can use it as a vehicle for providing support to parents to continue to care, but also support to parents to think about the future, and support to them to separate and build the independence of their adult with a disability. In the long term, that will then mean that you are not dealing with crises in your system of people who have never been away from home. And you are ensuring that people are at the maximum potential that they have when that parental care does stop. So you might reduce the amount of care that people are likely to need.

It is really hard to generalise. The research shows that there are typical profiles of older family carers. So the bulk of older family carers will have these sorts of characteristics. Obviously, there is diversity within that group and within family situations. But the chances are that older family carers are living in relatively small households. So it is usually a widowed mother who is doing the caring, on her own in a household with her son or daughter. But she may well have had other caring responsibilities, so she might still be caring for a husband; she might be caring for parents. They are very much this generation that is sandwiched in the middle of caring responsibilities.

With respect to the type of disability of this group of adults who are living with older carers, they tend to have a relatively mild disability, because the people with more severe disabilities were the people who were institutionalised and they are also the people who will have died. So it is the people with milder disabilities who continue to live with their parents and who will live into old age.

MS PORTER: This is a comment rather than a question. One would imagine that that profile will change over time, in that a lot more young people with quite severe disabilities are now remaining at home.

Prof Bigby: Yes.

MS PORTER: They are not being institutionalised as a norm. So those children will be staying at home with support, and that is the next cohort, which will be in some ways a more complex and more difficult issue for us.

Prof Bigby: Yes, and probably more diverse, too.

MS PORTER: And more diverse.

Prof Bigby: Because those people now with multiple complex needs are more likely to stay at home; you are right. Unless they have challenging behaviour, they are likely to stay at home. So it is the people with very severe challenging behaviour who often get out-of-home placements when they are young adults, because parents just cannot cope anymore. So the people who are relatively okay to support, who do not cause a lot of trouble, tend to stay at home. Similarly, the people with high, complex needs will continue to have a lower life expectancy. So the proportion of that group will get less and less as they age, relative to people with mild disabilities.

MS PORTER: Yes, of course.

Prof Bigby: It is important to recognise about this group of people that they are very adapted to caring. These people have been doing it for a long time, and most of the research that we have done shows that they often do not see themselves as carers, for a start; they see themselves as parents. They see it as just getting on with life, getting on with the family business. This is something they do; it is something they have always done and it is not necessarily a major problem for them.

MS PORTER: And the person being cared for has also adapted to being cared for in the same way, in that they have a built-in dependency, therefore, unless they are assisted to do the things that you are suggesting, to become more independent and to learn new skills—

Prof Bigby: Yes. One of the interesting things is that they are very happy. There is often this sense of mutual interdependence, of mutual caring. So the adult with a disability is often doing quite a bit of caring for their elderly parent. They often have quite a lot of skills that the parent supervises. There is some fantastic material that has just come out of the UK, some videos, which have a number of older carers talking about what their son or daughter does for them, and the son or daughter talking about what they do. So they will talk about “I do the shopping and mum writes a list and tells me what to buy” or “I help mum get out of the shower and do these things because she can’t do them anymore”. You get households where there is an interdependence. So who is the carer is actually very hard to work out. People are relatively okay with that situation and do not necessarily see it as a problem. So, as a group, these people are not necessarily jumping up and down, saying, “We need support,” because they have grown up without that support.

One of the added complications is the dual ageing. We know that at least half of people with Down syndrome will get early onset dementia. People with Down syndrome are likely to be getting early onset dementia at the same time as their parents who are in their 80s and 90s may be getting dementia. You get this issue of premature ageing. So the parent is trying to cope with the ageing of their son and daughter and trying to find age-related services for them at the same time.

THE ACTING CHAIR: Is that a fairly high percentage?

Prof Bigby: It is a huge percentage. Normally, people do not get dementia until they are in their 80s or 90s. There is a genetic cause for why people with Down syndrome get dementia, so a high proportion of them do—about 50 per cent—and they get it in their 40s and 50s rather than in their 80s and 90s. So that is a complicating factor.

Often, you find that the parents are fairly reticent about using services and having people in their home. It is not something that that generation have been particularly used to. By the time they are in their 70s or 80s, they will have had a whole procession of people through their house—social workers, support workers—telling them very different stories at very different times as to whether they have done the right thing or the wrong thing, whether they are too protective. So they are often fairly sceptical about support from outside. Although they are incredibly anxious about the future and what is going to happen when they die, they do not do a lot of planning for that. So engaging with planning and what is actually going to happen in the future is an enormous psychological challenge confronting this group of people and they do not tend to engage with it. "Everything will be okay" or they have unspoken expectations of other family members.

Certainly, the research shows that about a half to a third of parents have made no plans at all. The people who have made plans have tended to make informal plans that they have spoken to their sons or daughters about: "Will you make sure he is okay?" There is that very general handing over of responsibility to the next generation to be the advocate to make sure things are put in place, rather than make very firm, concrete arrangements for what is going to happen. They do not want any transition to happen until the last minute; so it is very hard to make very concrete plans.

One of the other issues is that most of the research shows that the adults with a disability are often sidetracked in the planning. Nobody talks to them about what is going to happen in the future. Parents might talk to their other sons or daughters but nobody will talk to the adult. Often the adult is very aware that they are going to have to leave home and mum is going to die or something is going to happen. They have thoughts about it too, but there is nobody to mediate that or talk to the whole group.

A lot of those adults have had no experience of being away from home. A lot of them go to a day program and have gone to a day program since they were little. It has changed with them into adulthood. In terms of spending nights away from home in other places with other people, they have not done that. That separation process has not begun to happen at all.

Consistently, parents are very anxious about what is going to happen in the future. They have not planned. They are very uncertain about the quality of care that they are going to get in the future. Often they have a fairly reticent view towards services. "Are services going to be able to provide care as good as I provide? We don't need services because we're okay now, thank you very much"—that type of thing.

If you take all those characteristics into account, there is a whole continuum of needs that you are likely to come across for this group of people. There are issues around planning and preparation for the future. I would argue—and I think some of the programs have demonstrated—that, if you provide low-level information and engagement for people thinking about the future and you do that in a consistent way in the context of a relationship, then people will begin to think about that.

You can use respite programs to begin to demonstrate that it is possible for the adult to separate and to do things on their own, often things that the parent has never imagined they could do. For example, there are some very good respite programs focused around this group of people. They have got together small groups of adults, taken them away for weekends or taken them away for holidays, often with the parents very anxious about whether their son or daughter will cope with that and then being really surprised about the things they have been able to do when they have been away.

The important thing is that the programs have engaged with the carer, the parent and with the adult and have fed back to the parent, via pictures and stories, the things that the adult has been able to do while they have been away. They have begun not only to talk about possibilities for the future but to rehearse and demonstrate them to show parents that these things are possible.

The respite programs have been used as a means to begin that separation and to begin things like doing life-story work with the adult so that their story of their life and who has been important to them and the things they have done is documented. It is there for when the parents are no longer around; otherwise, nobody is going to know their history if they are not able to communicate that. There are a whole range of tasks around the planning issues, beginning to engage parents in planning and the preparation for the future.

THE ACTING CHAIR: You said that some of these programs been used as part of the transition process. Do some of them connect with supported accommodation or at-home programs so that there is some continuity for the young adult? How has that worked?

Prof Bigby: The adults tend to be middle aged rather than young. The way they have worked is that they have acted as case managers. They have acted within a framework of case management. They have said, “We’re here to provide not necessarily ongoing, intensive work with the family but as a contact for the family, to begin to raise issues.” Some of the programs have done group work with parents. They have got groups of parents together to talk about the future and to talk about planning. They have done community education with them about wills and trusts, about accommodation options, what might be there.

Some of them have also begun to bring parents together to think about whether there are alternatives that they, as a group of parents, want to make. There is this using of the family capital for accommodation into the future. Many parents want to be able to do that but do not have good mechanisms for using their resources to provide for their adult son or daughter into the future. Some of the programs have begun to talk to parents around how they might do that and they have begun to see there is a bit of a linkage with other organisations that will help them develop some of those options.

MS PORTER: I have a question about this blocking of stuff with regard to facing up to the issue. I would imagine that is largely about facing one’s own death. It is like pre-grief stuff. As we know, part of grieving is denial. Do they want to deny that they are going to die and deny that their son or daughter will have to leave? How do they get through that emotional block that stops you thinking logically so that they can have these very constructive conversations?

Prof Bigby: Our research shows—and it has looked at a number of programs—that it depends on the case manager or whoever, whatever you are going to call them, is building up a relationship with the older parent and developing a sense of trust with the older parent. It is core social work skills about developing that trust. Often it takes nine, 12, 18 months to do that. The way to do that is to offer very practical support that is not challenging. Families talk about very concrete practical support and emotional support. They say things like "We wouldn't have been able to do that if the case manager hadn't been there, if she hadn't understood our situation."

One of the programs talked about this being a taxi voucher program. Often that is the only thing that parents will accept in the first place. They are not willing to let their son or daughter go to respite. They are not willing to have time away from them. They might accept a taxi voucher to go to a hospital appointment or they might expect the case manager to take them. Slowly you build up that trust and you begin that separation and those discussions.

MS PORTER: There is one-to-one work with the case worker, be it a social worker or whoever, and the family over a considerable time. It is very work intensive. It is very resource intensive.

Prof Bigby: I am not sure it is resource intensive because it goes at the pace that the family wants to go at. It is about having a continuous relationship with somebody but it is not necessarily having a continuous, intensive relationship. It can be variable, depending on what the carer wants at that particular time and what is happening.

We know that a lot of older carers end up in hospital because they fall or whatever. Older people end up in hospital more than other people. Often there comes a mini crisis where the person needs respite care for a short period. That is the beginning of building that out-of-home stuff. They try that and think, "That wasn't too bad." Then they do it next time.

The value of the program is that the person is known to the system, both the carer and the adult with a disability. When there is a need for that out-of-home stuff, it can be accomplished quite easily. It does not necessarily have to be accomplished by the person moving out of their house; it can be accomplished by a carer coming in. A lot of the adults that live at home with older carers are fairly skilled. Often they have not had the chance to exercise those skills.

There was a lovely case in one of our studies of a father who was widowed and who lived at home with his son. He was very clear that when he died he wanted his son to stay in the family home but the son had never spent a night in the family home without his father. The respite program, instead of sending the son off somewhere, sent the father off somewhere for a holiday and left the son at home and arranged drop-in support to check that he was okay. The program bought them a microwave because the son had learnt to do cooking at the day program but had never practised it at home because they did not have a microwave. The father cooked everything in saucepans. It is that preparation stuff that a respite program can start to do if they can have a long-term relationship with the family.

Our research suggests that this group of older carers, although they have been identified by the commonwealth as an important high-needs group, are often a poor fit to the existing services because they do not express high needs for support. They do not have very urgent needs. They do not often ask for support. Part of the programs that have been successful have also been doing outreach, trying to find people who have not identified themselves.

A small place like the ACT is very similar to some of the local government areas in the UK where they have built up registers of older carers and they know how many older carers there are. They are in touch with most of them in a very low-level way. They can predict what the needs are going to be in the future and can respond if there are hospitalisations and those sorts of things. They are often very hard to engage. Relationships are very important. Parents value concrete and emotional support. The support needs to be long term, intermittent and variable.

The other thing to remember is that parents often engage with multiple systems. There are a whole range of very fragmented services, each of which may have a very narrow focus and not see the bigger context of the person with a disability and the carer. You may have a person with a disability who goes to a day program. That takes care of 3 to 5 during the day. The family may be getting a home help from the local government HACCS. Neither of those two services is actually thinking about the needs of this family as a whole and what is going to happen in the future when the carer cannot care anymore or the carer has to go to hospital. You often end up with a situation where families have got multiple people coming in but nobody seeing the whole picture or working with them around the whole picture.

It is fairly complicated work. I think people tend to see respite programs as fairly simple, that they are just about providing a break and time for people away. If you are going to be true to the principles of self-direction and social inclusion of both the adult and the carer, then you need to engage with the family as a whole and to do family-focused adult work, which is very different from doing work with families and children.

The adults are persons in their own right, and their needs may not be commensurate with the needs of the parents. In children’s work, usually if things are okay with the parent and the parent’s needs are met, then the needs of the child are met. In adult work that is not necessarily the same. The needs of the parent may conflict with the needs of the adult.

MS PORTER: There have been some recent studies, I think, of children who are homeless with their families, and they found that the children’s voices up until this point have not been heard effectively. They can actually perceive different things from their parents about that situation. So it is interesting to see how much we maybe take some of these things for granted.

Prof Bigby: I think that is true, and I think if children are not heard in families then adults in families are heard even less, because it is much easier to talk to the carer. The carer is articulate, whereas the adult is often not able to express their needs particularly well and has not had a chance to do that. And engaging with adults with intellectual disabilities who do not have good communication skills is a fairly complicated type of work.

I think what has happened with government policy is that it has focussed on carers, so it has been the carer who has been seen as the client, rather than the carer and the person with a disability and the family unit in that context. It has been a very simple sort of knee jerk reaction, I think, just to look at carers rather than at the more complex situation.

As I am sure you are aware, federally there was the whole range of initiatives that came out two or three or four years ago, which tended to just provide short periods of respite, so the programs were seen in terms of two to four weeks of respite for particular groups of older carers. Again, it was just this very tangible short-term breaks approach. That was how they were conceived, rather than being part of a program that would be much more useful. There was no focus on finding people; there was no focus on thinking about the future.

And they were often delivered through non-government organisations and through the federal government’s carer respite centres, which bypassed disability services, so again they did not connect with the people who were already part of the system and bring that picture together. So they were very fragmented and very difficult to navigate.

And there is the other half to the story. There are the carer packages and then there have been the in-home support packages, targeted either at people with disabilities or at older people. So you can have families where you have various programs going in, with small bits of packages—again none of them sort of seeing the whole picture. We have an example in one of our reports where there are five separate programs going in to a family, and most of those are respite programs that have been funded under different initiatives.

That might sound really good: you are getting five packages of respite. But, if they are not coordinated with each other and they are trying to offer the same thing at the same time or a different thing at the same time, then you are not getting as much out of them as you should. And it is very confusing for older carers. They do not know where people come from.

So there is this real problem of the way in which programs have grown and are not coordinated together. One of the things that I think some of the states have tried to do is to bring all the respite programs together, to bring all the funding together and say, “We are going to use it for a really well-developed program with some clear targets.” In Victoria one of the things they did was an older person’s planning service, which was just focussed on older carers and brought a range of that commonwealth money together.

But even then they found there was difficulty. Then they invented this other one where they funded Centrelink to ring up older carers to ask if they needed respite. So people would get a call out of the blue, “Do you want any respite?” and it was very hard to know what people were talking about.

THE ACTING CHAIR: Is that program you were talking about—the coordinating service for older people—through HACC funding or separate of HACC?

Prof Bigby: The one that we evaluated a couple of years ago was not HACC; it was a blend of carers money from the commonwealth and some existing carer money from the state. One of the problems with that was that, because it was sitting in the carer policy domain, they had real struggles, saying, ‘Okay, who is our client here? If the needs of the adult conflict with the needs of the carer, do we have a right to work with the adult as well, or do we just ignore that and meet the needs of the carer?” For most of the time, it was okay, and one of the programs was more able to deal with that than the other one.

THE ACTING CHAIR: Have you looked at the HACC funding model at all? A lot of the respite in the ACT comes through HACC. Some of the things we have heard are about how it has very specific requirements that need to be followed and I am wondering whether or not that allows for that case management approach, as you said, which is required probably for all families really but specifically for these sorts of families. Does it allow for that or does it restrict it in a way?

Prof Bigby: The HACC in Victoria comes through either local government services, in which you get a very small bit of respite—so many hours a week; it is very small—or you might get it through the linkages program, which does provide case management. But the linkages lrogram is targeted at people with very high support needs and urgent needs.

This group of people, whose needs are much more about prevention and maintenance, do not figure very highly in the linkages program, unless there is a crisis. I guess our argument would be that you need some of these fairly low level preventative programs so that people do not end up in a crisis. Crises are much more expensive and, obviously, they are much more disturbing for the adult with a disability and for the older carer. It is one thing to talk about the difficulty of the service system responding to crisis, but it is also the human experience of people having to leave their home, when they have never left before, and go to live somewhere completely different, overnight almost, without any sort of understanding or experience of that.

Just to sum up, there are overarching policy problems: there are no population based planning or benchmarks around this group of people, there is a huge unmet need for accommodation which overshadows proactive planning and there is a whole range of government funding and programs with almost no coordination between them. So our argument would be that you need to think about respite within the context of the programs that already exist. There are very few mechanisms or programs that allow a focus on the older carer and the adult with a disability, and the programs that have been developed have been very partial and very few have taken a comprehensive approach to needs and focussed on ideas about prevention and actual proactive engagement about planning for the future.

I think there needs to be, obviously, much better data, so you know who you are planning for, there needs to be some benchmarks around accommodation support and unmet need and you need family-based in-home support packages that will blend together the needs of the adult and the needs of the carers so that you could construct a respite program around older carers that had a focus on outreach and prevention and that would support, in a casework framework, continued caring and preparation for the future and could broker flexible respite options, either in or out of the home, either group or individual, depending on individual needs.

You do not need to construct great big houses or respite type activities: you need to have funds available so that you can buy into things that are already there, depending on what is most appropriate for that family at that particular point of time. Or, if you do have a program that is dedicated to this group of people, they could construct some of those things, so that people could choose them if they wanted to.

A program could have a key role in sort of preparing for separation and independence and beginning to expand people's social networks and it could be based on longer-term engagement and building of those relationships with the carer, the family and the siblings, with the rest of the family. Often the carer programs just focus on the carer and the adult, but we know that it is the siblings and other family members that are most likely to step in and do that informal sort of management of that transition. So those people need to be engaged in some thinking about the future too and in understanding what the service system is like and how to use it.

You were saying how psychologically challenging it is for parents to deal with planning. It is often the case that the siblings will actually take the responsibility for that, bypass their parents completely and say, "Look, it's time now." They will go and look for alternatives and do that work—behind the parents' back almost—and make it a fait accompli for the parents. And often the parents are quite happy about that because it has taken the responsibility away from them. These types of programs could also have the capacity, obviously, to refer people when they need high levels of support. So I think the respite type of prevention program is for people who need relatively low support but need engagement and discussion about this planning issue.

Such a program could also begin to coordinate and consult with the generic programs that people might already be in touch with—things like the district nursing services, the HACC programs, linkage programs and day programs for adults. All of those services are in touch with older carers and need to be aware of the bigger picture. If they were aware, they would in the end reduce the need for a specialist program to target this group of people.

The carers association did quite a lot of work on this a couple of years ago, and it is worth looking at some of their stuff if you have not done so. Gill Pierce, who is the policy officer, has developed a whole sort of blueprints almost for a respite program for older carers and has set out what that might do and its aims and objectives. I think they were quite close to getting support for that from the federal government and then for some reason all that stuff dissipated again.

There are other obvious things that go along with older carers. There are some really good examples of engaging the legal profession around disseminating and promotion of wills and trusts for thinking about the future. Patrick Keyser in Queensland has done some really nice work with some of the big law firms on a pro bono basis to get up some really accessible information.

I think any system has to think about how it is going to expand the range of housing options into the future. One of the tragic things that happen sometimes with people who are living with older carers is that the older parent becomes incapacitated, nobody can take on that day to day support and people end up living in respite, because there is nowhere else to live. Then respite gets clogged up and that then reduces the support available to other families.

That is a potted history of the issues around older carers and why you could use respite to focus on this group of people and to focus in a much more coherent way, rather than just adding another little bit to all the federal programs that already exist.

THE ACTING CHAIR: You mentioned the linkages program. Are there any examples of where this sort of program has been ongoing and continues to operate, whether it is in Australia or anywhere else?

Prof Bigby: Yes. We have done an evaluation of a program that was done in two regions in Victoria, which was called the older family support program, which bundled together some of that respite money. That is still going. I think I sent to Grace a copy of the evaluation, which sort of describes what the program does and the situation of some of the carers and their views around it.

There are some really interesting programs overseas. There is an organisation called the Foundation for People with Learning Disabilities, based in London, and they have auspiced a number of older carer programs, one particularly in Sheffield. I cannot remember exactly what it is called but it was run by a woman called Dalia, who came out a couple of years ago and spoke extensively about that program. They have a register, so they keep in touch with everybody on the register and have begun to try to persuade people to do planning. They have some great materials to resource workers who are working in the field now. So there are some really good examples, and a number have popped up around Australia too, but to my knowledge very few have been evaluated. As a researcher, you hear about programs. People will say, “This is a really good program,” and you have to ask the question: how do you know? So you need to look at evaluations.

We did an evaluation a number of years ago of one of the first older carer programs, which again I can make available to you, and that is still continuing in Victoria. It got re-auspiced. It is based at the Nillumbik Community Health Service and it is called options for older families. They have now been doing that work for about 10 years. So, yes, there are examples.

The important thing is that these programs are not intensive programs; they are preventative programs that use the money in a holistic way rather than just looking at immediate needs. They look at the immediate needs in the context of the bigger long-term picture.

MS PORTER: You were saying there is not much data available. Has there been any approach or any work done in looking at how different cultures are dealing with this issue? I was involved in the volunteer movement, travelling around Australia and around the world in different places where volunteering had not been common, say in Asia and places like that where people have always cared for their family members, for instance, so that volunteering to look after somebody else's person who needed caring for was not done—until the family structure started to break down. The family living together started to fragment and change from having these big families where everyone lived within cooee of one another.

Therefore, there was a hidden problem and some people with disabilities were going out on to the street because there was nowhere else for them to be during the day. I was wondering whether there has been any study about how they culturally approach that changing dynamic. We do have a very diverse population in the ACT—extremely diverse, also in Australia, but particularly in the ACT. We have people from all the different countries.

Prof Bigby: That is a very pertinent question. In terms of children and young people, there has been a fair amount of work about cultural differences and attitudes, particularly from the UK, that has looked at minority groups and their attitudes towards people with disability. There has not been a lot of work in Australia. There is an advocacy group in Melbourne that looks at ethnic communities, and the sense very clearly is that the use of services of people from ethnic communities is much lower than it is amongst the Australian population.

In terms of this group of people I am talking about in terms of older carers, the situation is that, because we have had such a discriminatory immigration policy, migrants have not been able to come to Australia with their disabled children. So we do not have that problem amongst this group of people, but we will have it in the future. And, again, that goes to the importance of outreach and of finding people, because people will not come and ask for help if they have an attitude in their culture that they do not need help, that help is shameful or that they are going to be blamed. That is why you need programs that reach out to people and slowly provide support that people can trust, to bring them within the services—not because we want to make people dependent but because it is really important because their support structures are going to break down sooner or later.

MS PORTER: We have been talking a lot about people who are born with a disability, but I guess there is a group of people out there with acquired disabilities, acquired brain injury, who could be living at home with an ageing parent—people who have come to live here and had an accident, and also people born in Australia.

Prof Bigby: And the other group of people are the people with mental illness who are living with carers. Some research has been done on that issue in the States which shows that that group of older carers is even more stressed than anybody else because they have got that anxiety about the future and because the caring that they do is not long term and stable; it is intermittent and episodic. We know almost nothing about that group of people in Australia, and I think they are a growing group. As you say, the number of people with ABIs is predicted to be similar to the number of people with intellectual disabilities in the future. That is a relatively large population. Again, there is lots of medical-type research but there is very little social research about their conditions, their circumstances, their social networks and their support. With respect to people with intellectual disabilities, it is a long-term group where there has been lots of research overseas, and research in that same sort of discipline group. People have not looked at those new issues for the other groups, and we have not done comparative studies.

THE ACTING CHAIR: With mental health as well, because de-institutionalisation occurred and people went into the community or went to families, there has not really been that examination of what the impact has been on society as a whole and on services as a whole, and particularly on carers who have had to take on that responsibility. And it is so episodic and intermittent. Someone might be away but then they might come home for a time.

Prof Bigby: Or they might be well and then they might be ill, whereas caring for someone with an intellectual disability tends to be more ongoing and stable. The other thing is that when de-institutionalisation occurred for people with intellectual disabilities, almost nobody was made homeless, because people were too dependent for that to happen. But for people with mental illness, that process was not as effective in terms of providing alternative accommodation.

THE ACTING CHAIR: You mentioned working with some families about creating their own options in terms of living arrangements for the person they care for. I know there are a couple of groups in the ACT working on independent-type living models or having the person they care for be able to live in an arrangement so that, if something happens to them, they are living in that arrangement. It is a matter of that sort of transition. Are there any successful examples of that? Have there been any evaluations of those types of living arrangements?

Prof Bigby: The short answer is no. There have been a number of initiatives where, not in a planned way but in a more individualistic way, older carers have moved into nursing homes or aged-care accommodation with their middle-aged adult with an intellectual disability because they could not be separated or because it was felt to be the appropriate thing to do. That is really problematic because the parent then dies and you then have this 50-year-old person in residential aged care.

MS PORTER: If they have a lease, because sometimes they do not.

Prof Bigby: Then they may be turned down.

MS PORTER: Yes, I know that; I am working on some retirement village legislation at the moment. There is a problem there.

Prof Bigby: I came across, in one of the studies I did, a parent who had negotiated with one of the charitable religious organisations that had a retirement village. They had bought a house on it and they said, “Okay, I’ll give you the house; you can keep it when I die, as long as you look after my son,” which they did. But it is a matter of whether it was appropriate for him to be in that setting. So there is a real issue with future planning, and that is a whole other story. The issue is that parents want people to be safe and secure in the long term, but you cannot plan for the rest of somebody’s life, when you are talking about 40 or 50 years, because policies are going to change, people’s lives are going to change, people’s skills are going to change. All you can plan for is that first transition. So you need to be able to put together arrangements that can be changed, that can be flexible, which means you need somebody who is going to act as your advocate to negotiate those formal support services and to be able to change them as necessary.

In Victoria, there are a number of schemes where there is shared equity. So it has enabled parents to put equity into supported accommodation—to buy a place, in a sense, in shared supported accommodation—which they can then buy out of again, which is, I guess, similar to retirement-type things. But there is this growing trend, particularly in New South Wales, towards bigger clusters of accommodation, which some people would argue is completely contrary to the current "valued" policy position. As long as you continue to cluster people together, they will continue to be seen as separate, different and less valued than other members of the community. But it is a response to the fact that there is no other accommodation available.

THE ACTING CHAIR: There are a couple of groups in the ACT trying to pursue that sort of model. I think they put that argument, "We don't want group houses." Somehow they are separate but then there is this argument by some of these families, "We want to have them there with the social networks." You can't plan for everything that is going to happen, but it is with the idea that we want to have some option there for them, because there is not any other option that they can see or can think of. They want something that provides some sense of familiarity for the person they care for when they are unable to support them.

MS PORTER: You say that to this point there has been no evaluation of those larger kind of residential programs?

Prof Bigby: Well, yes, there is. There is a huge swag of literature about larger residential programs for people with disabilities, which are called institutions.

MS PORTER: No, I am talking about separate living arrangements where people buy into, say—

Prof Bigby: Cluster.

MS PORTER: a cluster, which is a large cluster, but they all have their own independent living unit and there is support on site. I think this is one of the models that has been suggested, where there is support on site for them, to help with various care that they might need in an emergency or whatever. Do you know of any models that exist anywhere in Australia or overseas of that type and whether they have been evaluated?

Prof Bigby: It depends how big they are. A paper came out at the beginning of this year by Jim Mansell and Julie Beadle-Brown which looked at a comparison of outcomes for cluster housing, as opposed to small group homes. They are from the Tizard Centre. I can send you the reference, if you like. They say there is very little research around this.

It is really interesting because people talk about intentional villages and that it would be nice for people to have their own networks and things. Intentional villages are another thing again—the L'Arche communities and Camphill in the UK. They are based on particular religious philosophies. It is about people sharing their lives with people with disabilities. So the people that work in those villages do not work there; that is their life. So they are freely given relationships where people choose to go and live in a setting with other people, with people with disabilities. You cannot re-create that sort of community with paid staff. Often, the intentional village and the relatively okay outcomes from there, although again only for people with milder disabilities, cannot be contrasted with the outcomes from some of these newer, intentionally created villages that have paid staff. So we have this increasing sort of diversity.

Often, the cluster arrangements have been put in place because of the failure of small group homes or because of the unavailability of small group homes. I guess my argument would always be: why are we asking these questions? Why don't we try and make the group homes better? We know there are some really good group homes and you can do great stuff in a group home setting, but most of them do not. So that is an issue about implementation rather than the model itself. There is an enormous amount of literature about research on the different types of accommodation models and the pros and cons of each.

I think one of the problems is that some families want to be proactive and there have not been mechanisms that the government has supported to enable them to use their capital funds to be proactive. They have been forced outside of the system. Then you get a stand-off sometimes between government and groups of parents who, at the end of the day, all have the same common purpose, in a sense. But when carers tend to dominate there needs to be somebody who is saying, "And what about the people with disabilities? What do they want? Is this in their best interests or is it just meeting the needs of the carer?" That is very hard to do with parents who you know have the person's best interests from their point of view.

MS PORTER: Then all the other emotions that are in the grief come in, like anger and so on.

Prof Bigby: That is right. We have treated parents very badly in the past. My profession has blamed parents for some of the things that they have done in the past. It has accused them of being overprotective and those sorts of things because we do not see the life that they have led and the way the policies have changed. Young social workers come in and say, "Hey, you're not in tune with current policy," and they forget what the person has been through. This is a very highly skilled area of work that involves a lot of complex work with families with conflicting needs. You need to resource it so you can afford to use professionals who can deal with those situations.

MS PORTER: I think that comes back to my statement. I think it is resource intensive. I am interested in the debate that is going on at the moment about whether or not we need a type of insurance policy for all of us to pay into. We need it for disability. The whole question of how we fund all of this is another question. It is for the federal government, I guess, to prosecute that. In the meantime, the ACT government need to grapple with how we respond.

Prof Bigby: I think one of the things with disability is that there is no right at the moment to services. There is a huge amount of unmet need. That gets in the way of good quality services because you are trying to manage that demand and you are dealing with crises rather than responding in a much more planned, proactive way.

THE ACTING CHAIR: I wrote down that one of the issues that you listed as a policy problem was inadequate growth funding. That has been another issue, obviously, which has come up. It is a difficult thing to do in disability because once someone has a disability it is something which will continue throughout their life; whereas when you apply growth funding to health, people's circumstances can go up and down. Is that something you have looked into? I know it is a very complex issue. How can the issue of growth funding for disability be addressed? How can you determine what is an appropriate level of growth funding in disability? I know it is a huge issue.

Prof Bigby: Part of the problem in Australia is that we do not have any population-based data. We do not know the size of the problem that we are trying to deal with and we have not costed it well. I think that the Productivity Commission is going to be doing a lot of the work around that. If you look even at aged care, aged care has formula-like funding and it changes depending on somebody's increasing level of need. You can move from low to high care and the funding to the organisation increases. If you are in a disability group home, for instance, there is no mechanism to take account of the fact that you are ageing and that your needs are increasing. You have to do that one by one. Organisations have to negotiate with the funding body about some of these changes. We do not manage those big picture funding mechanisms very well at all in disability. Somehow disability got left behind in the sophistication of existence.

THE ACTING CHAIR: Do you have any further questions?

MS PORTER: No, I do not. It has been very interesting and I thank you very much.

THE ACTING CHAIR: It has been fantastic and very enlightening in a lot of areas. Thank you very much. Some of the references you provided to us will be extremely useful in terms of some of the issues which have come up.

Prof Bigby: I have sent you some of those reports and I can send you a copy of this, if you like.

THE ACTING CHAIR: That would be great. A transcript of the hearing will be sent to you so if you can just check that for accuracy. Once again, thank you very much for appearing before the committee.

The committee adjourned at 11.41 am.