FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into the provision of supported accommodation for Victorians with a disability or mental illness

Melbourne — 22 October 2008

Members

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Ms G Pierce, program manager, policy and research,
Ms L Hillman, policy adviser, and
Mr B Ilsley, policy adviser, Carers Victoria.
The CHAIR — Thank you very much for coming along to the public hearing. This is the Family and Community Development Committee, which is inquiring into residential supported accommodation. I am the chair of the committee. The committee is looking into issues such as the standard, range and adequacy of care and accommodation currently available; the appropriateness of the current service providers; how unmet need is managed in Victoria; accessibility and appropriateness of accommodation for rural communities, ethnically diverse communities and indigenous Victorians; and the impact of the current service provision on families and carers. This is an all-party investigatory committee of the Victorian Parliament and is due to report to Parliament by 30 June next year, after which the government has up to six months to reply to the committee’s report and recommendations.

All evidence taken at these hearings is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Parliamentary Committees Act 2003, the Defamation Act 2005 and, where applicable, the provisions of reciprocal legislation in other Australian states and territories. Any comments a witness makes outside the hearing may not be afforded such privilege. We are recording the evidence and will provide a proof version of the transcript to each witness at the earliest opportunity so that it can be corrected as appropriate. I ask for cooperation from members of the gallery. Please do not make any comments or interjections, because this will interfere with the recording.

Ms PIERCE — Carers Victoria thanks the Family and Community Development Committee for the opportunity to present and respond to questions about our submission. I am Gill Pierce, program manager, policy and research, at Carers Victoria.

Ms HILLMAN — I am Leigh Hillman. I am a policy adviser for Carers Victoria.

Mr ILSLEY — I am Ben Ilsley, I am a policy adviser at Carers Victoria.

Ms PIERCE — As the peak advocacy organisation representing people caring in Victoria we value the opportunity to influence policy change in this crucial area of need for family carers, and we will be watching closely for the report of the committee to see that its recommendations contribute to improving the lives of those who are caring now and those who will be caring in the future.

I need to extend apologies from Maria Bohan, our chief executive officer, who is unable to be here. You probably know that this is Carers Week, and Maria is booked up for Carers Week months in advance, so it was not possible to change those arrangements. Our presentation is going to take place in two parts. Firstly, Leigh will outline key issues and carer concerns about supported accommodation for people with a disability. Ben will then present key issues for family carers about accommodation and support for people with a mental illness. All of us will be happy to respond to questions from the committee. Essentially it is our view that the current supported accommodation system in Victoria is grossly inadequate. As a consequence of that it carries enormous costs and risks, both for family carers and for people with a disability or a mental illness.

Ms HILLMAN — Just before I start would like to draw your attention to page 3 of the briefing paper on disability. I have to apologise for a typo, which I only just noticed last night after everything had been run off. In section 1.1, headed ‘Respite and social support’, the second paragraph says, ‘Despite this developing work’; it needs to say, ‘Despite developing work by DHS’. It would be rather unfair to DHS not to address that before I start. What I thought I would do is give you a snapshot of the statistics in relation to people with disabilities and their carers in Victoria. I would like to also speak briefly about the issues around the current crises in supported accommodation. I know other speakers at the hearings will address these issues, but I would just like to address them somewhat. Then I will talk with you about the impact on two particular cohorts of carers — older parent carers, whom I noticed you already have a very strong interest in, and also parents of younger children and adolescents. At the end of my section of the brief there
are some recommendations, and I would be happy if you wanted to run through those during the question time, to address them with Gill and Ben as well.

In Victoria there are over 990,000 people with disabilities, and of those 990,000 approximately 30 per cent are considered to have a severe or profound limitation that will inhibit their ability to care for themselves, to communicate clearly or to undertake normal cognitive or motor development tasks. For those people there are 690,000 unpaid family carers. This includes 116,600 primary carers, who provide most of the support and assistance required for a parent, a partner, a child or a friend with a disability or chronic illness. The Productivity Commission’s 2008 Report On Government Services shows that in Victoria just over 4 per cent of the potential population of people with disabilities accessed accommodation support services, while 20 per cent accessed funded community support services in 2005–2006. Of those service users approximately 45 per cent had profound limitations, 45 per cent had severe limitations and 10 per cent had moderate to no limitations. I think it is fair to say that these figures demonstrate that Victorian carers currently are providing the vast majority of support for people with severe and profound disabilities. I know sometimes you can dispute statistics, but on this occasion I am certainly not going to be the first one to dispute them.

Carers are undersupported by the essential formal respite, accommodation and other services, for which there is significant demand throughout Victoria. I think it is very important to preface any further discussion by stating at this hearing that supported accommodation is far more than bricks and mortar. It is not just the building; it is not just the roof over your head. It requires an ongoing and sustainable investment by government to provide flexible accommodation models, the workforce to implement those models successfully, and the support services that enable people with disabilities and their carers to enjoy the social connectedness that Victorians take for granted.

The current crisis has already been alluded to in the hearings this morning, but I think it is important to state that at June 2008 the disability support register had recorded 1358 people waiting for disability support accommodation options. Add to that another 1282 people who were awaiting in-home support to assist them to live in the community, and I think it is fair to say that whilst I have been very polite in this paper by referring to a ‘current context’, we are actually dealing with a crisis.

In relation to respite, the Auditor-General’s report has been very clear that in some cases, and I quote:

… respite care was used to meet the accommodation needs of a person on the DSR awaiting SSA.

I think that raises very serious concerns as to the impact on the carers of those people. DHS, I know, are attempting to deal with this issue. We have had correspondence with them on that, but it is a very slow process, I think, even with the best of intentions by departmental staff. They need the resources and the financial backup to deal with this over a very much more protracted period of time. I think Marsha Sheridan spoke very well to that this morning in informing you in a more detailed way about it. The difficulty of the loss of those respite places due to having to be used for dealing with more emergency crisis needs for people at risk of homelessness and loss of accommodation is that it really causes some very desperate situations for families who seek short-term respite simply so they can continue their caring in a positive and supportive way. They are at risk of losing that capacity.

In relation to medium and long-term accommodation, the needs of carers and the needs of the people for whom they care can change very rapidly as a consequence of family crisis, a breakdown in the health of the carer, a breakdown in the health of the person with the disability or the carer’s death — and again, I know that was touched on this morning. So it is essential that long-term care plans and emergency and succession plans are developed and understood between family and social and professional networks prior to those crises occurring, and it must be a collaborative effort. It cannot be done by a service provider, a DHS worker or a family working in
isolation. I think it is fair to say that carers should be regarded as the partners in planning. They are the people who know best the person for whom they care. They have a great level of knowledge and expertise, and I think you would have heard that from some of the older carers who presented to you just before the lunch break today.

The difficult thing is the current system cannot effectively respond to either the long-term planning needs or the crises of families because there is a lack of resources and because there is this issue of ‘bed block’, as we call it, within the respite system. It just creates a backup, so families seeking those longer-term and medium-term solutions are left stranded.

The other issue is that there is a reaction by the system in trying to accommodate people. This has major risks, and most of them relate to inappropriate accommodation for people. They are placed in facilities or in housing where there is incompatibility, and there is major geographical dislocation from their family — and I should say that even though you move out from the home as a person with a disability, your carers do not stop caring. Carers continue to care even if the person is living independently of the family unit.

The community visitors report of 2008 also raised a really major issue, and that is that people who are already resident in a facility, a CRU or whatever housing they have been placed in whose needs change or for whom incompatibilities arise — whether around medical issues or the needs of other residents — cannot move out of their original place of residence into more suitable housing because there are simply no other options.

Once you are in an accommodation placement you almost stay there; you do not shift with the change of your needs. I think that is an issue that often gets a little bit overlooked.

There are also issues for carers in relation to private market accommodation options where you have people who have not got disabilities that are so severe or so known that they warrant crisis intervention but whose disabilities will still impact detrimentally upon their decision-making capacity. They get left; they fall between the gaps. They are at risk of falling between gaps because the current system responds to high-need, crisis and profound issues. What we have been seeing and what carers raise as a major concern is that their family members with the disability will end up within rental in a private market in environments such as boarding houses or hostels, or in supported residential units. One of the difficulties of relying on the private market is that accommodation is provided, but these people who are seeking the accommodation may well already be marginalised, they may be very vulnerable to exploitation, and they are unable to seek alternate services from a provider because there is already an accommodation shortage. There is no point going to a service provider if you know they have nowhere for you.

Private market accommodation in relation, particularly, to SRSs — and boarding houses to a degree — may at times appear relatively affordable for people, but we are talking about people on disability support pensions. Their income levels are not high. There are a couple of issues there. One is that these sorts of facilities in the private market do not assist with the holistic support that people need. As I said before, they do not simply need a roof over their head; they need support and services surrounding them to help them with their personal care needs, their vocational needs and their social skills and social inclusion.

The other difficulty which I think is very important to remember is that entering something like an SRS or entering a boarding house is really another congregate model for people. For some, they have moved from segregated institutions originally, if you look at the experience of Kew Cottages, but because they have not been able to enter more individualised accommodation support, they go into boarding houses or they enter SRSs, and they are just one of another 50 or so people. That causes great concern to carers, because all they see is the person they care for left with no safety net. I think there are major issues that government needs to address in the regulation of those sorts of facilities in relation to the workforce; in relation to the mixes of residents, regarding gender and challenging behaviours; and in relation to the lack of support and
the lack of health resources within those boarding houses and SRSs that are all detrimental to the person with the disability.

It is very important when people enter supported accommodation that that planning is done in a holistic manner. Housing and support services are not independent of each other; they have to be planned and they have to be coordinated together. Again, they have to be planned in accordance with the change in need of the person. They have to be complementary so that that person with the disability can really reach the goals they set for their needs and their aspirations. Those are needs and aspirations that are usually shared by their carers. There is very little disparity between the two. The issue for carers is: is my family member going to be safe? To put it in very simplistic terms: are they going to have a good and happy life?

Other presenters have spoken about the disability workforce today, so I will not go through that again. You will be able to read that. One of the issues that was touched on this morning briefly was about people with disabilities ageing. I would just like to talk briefly about the issues around service system interfaces and government interface. In 1997 the concept of ageing in placements was actually enshrined in the Aged Care Act. It legislates that people can remain in their home — however their home is defined — regardless of increasing care needs.

We need to see a new system where people receive complementary combinations of support from both the disability and the aged-care service sectors. Separate funding programs, the lack of collaborative planning between the commonwealth and the state governments and the impact of competition policy have really led to increases in fragmentation of services, particular targeted to ageing parent carers. There is a lot of confusion among carers about who you approach for what need and about their perception perhaps at times that there is duplication between programs. There are at times unnecessary restrictions on program eligibility which exclude ageing parents, who are very needy. There is a poor recognition of the need to support ageing parents and their families while there is this planning and implementation of future care arrangements.

In relation to the older carers, there is really a major impact of this current crisis upon them. The Auditor-General has made a very strong note in his report regarding the impact on carers and stating that they need support themselves as well as the person for whom they care. Carers, particularly those over 65, will have significant health issues. They have grave concerns about the future of their son, their daughter or the other relative they care for. Many older carers have been caring for extensive periods of time — up to 50 years — and it is a long time to suddenly be told, ‘You have to make a change’.

We cannot assume that informal and ongoing family care is going to be available or desirable when the long-term primary carer, such as the parent, is not available to care. There are expectations for people with disabilities now that they will want to live in the community with supports, as is being looked at through individual support programs and funding. The other issue is that there were previous generations who were less likely to outlive their parents and who would be cared for through institutional arrangements. That is not the option now. Most people — and it is increasing — with disabilities will actually outlive their parents. That causes this issue to be a priority, we believe, in government planning.

There needs to be a very strong balance between planned and supported transition from parent care. We need to ensure that there is a capacity within the system, government and non-government, for emergency or sudden transitions for people with disabilities. They require well-resourced service providers through adequate government funding. Parents and other family members must constantly be included in those processes of planning and actual implementation on individual levels, and obviously Carers Victoria must be included on a systems level. Again, the Auditor-General has raised this with great emphasis in the last report.

One of the cohorts that has not been touched on so far during this hearing is parents of children and adolescents. There has certainly been a trend in relation to children with particularly severe
disabilities not to be institutionalised now, as opposed to that old model where, if you had a child with severe disabilities, invariably parents would be expected to make a decision that their child enter institutional care. There is an objective now within government and professional policy and opinion that children with disabilities should be living with their families, particularly children with severe disabilities. There is a preference that it be their birth family, but failing that, if there is a breakdown in the child living with their birth family, there is a view that the child should go to foster family care or substitute family care of some sort.

I think it is fair to say it is essential that we address the supported accommodation needs for children and adolescents in a preventive manner. If there is a strong philosophy that children should remain with family, the preventions and the strategies to enable that to happen need to be strengthened. I think it is also fair to say that those strategies will enable the child to grow within their family, which is the natural authority on that child’s needs and on that child’s requirements and aspirations again. But the cost of caring for children with special-care needs is extremely high. They have greater requirements for primary and specialist medical care. Therapeutic and supportive services like rehabilitation aids, equipment, home help and respite care all cost money for these families, and there are numerous studies that indicate that given the level of financial disadvantage parents are placed in — not grudgingly whatsoever — the reality is they are having to operate at a far lower financial level because of the costs incurred to maintain their child within their family unit. I think it is a comparison we have to make where, when children with disabilities enter the substitute care system or the child protection system, the expenditure to maintain the child in that placement in substitute care far outweighs the costs that are currently incurred in relation to providing effective and suitable support services, including respite, to parents and other carers. I should include grandparent carers in that broad comment as well, because they are certainly a group of people who are coming forth more and more caring for kids with disabilities.

It is really essential that government provide an early investment in the provision of appropriate respite for families and also the other holistic supports required. Again, it is not about supported accommodation or respite in home or out of home in isolation. You have to make sure there is a holistic package provided that really provides the family with the resilience and capacity to continue as a family unit. There is certainly an economic argument for this. The cost of respite care to the state, and hence to the taxpayer, is enormous, and I do not think anyone here would begrudge that money being spent when children are in respite care, but the long-term economic argument is that it will cost the taxpayer far less than having to expend money on foster payments and on additional resources to foster parents to ensure that the child can at least stay in a long-term substitute care placement if they cannot stay with their family. Too many kids go through the foster care system changing placements, whether they have disabilities or whether they are able-bodied as well. There are major disadvantages to any child entering substitute care. I will now pass to Ben.

Mr ILSLEY — I would like to make some brief comments about housing support for people with mental health problems, and a more detailed written submission is to follow. I am aware that time is limited, so I am going to go straight to some of the key messages and, if I outline these, we will hopefully get the opportunity to return to some of them in more detail as we go. The first one is that housing support is a key issue for carers of people with a mental illness. Whenever we have meetings or focus groups or whenever studies are done as to what the most important needs are expressed by carers of people with mental illness. Whenever we have meetings or focus groups or whenever studies are done as to what the most important needs are expressed by carers of people with mental illness, accommodation and housing comes up every single time. I will say a little bit about why that might be in a minute.

There is clearly a shortage of housing and home support in this area, but there is also a lack of adequate data about need or demand, so when we are talking about the scale of the problem it is quite hard to ascertain how big it is, but what we do know is that we have data about the secondary sorts of effects — the indirect effects — of not having adequate housing and support. For example, we know that many people who are homeless have mental health problems. There is a very strong link between homelessness and mental health problems. Recent studies have shown that in Melbourne, for example, 50 per cent of people who are homeless are likely to generate or
develop a mental health problem, but we also know that people who have mental health problems are much more likely to become homeless, so we know there is a very close relationship between the two issues, and also the link between housing support and recovery from mental illness is a crucial link. We know that that is one of the indirect effects of this problem.

We also know that the mental health system is in crisis. I am sure some of you have seen the full-page article in the *Age* today about some of the problems the mental health system is having. We have pretty good data and some good studies; Boston Consulting Group did one in 2006 analysing some blockages in the system. People just cannot access the acute services they need because the beds are blocked, often because there is nowhere else for those people to go. They cannot discharge them anyway because there are not any accommodation, housing or support options, so there is a sort of a ripple effect where almost the entirety of this sort of very expensive acute system is blocked up with people who should be elsewhere for their own benefit and also for the taxpayers benefit.

I am going to make an argument for investment in housing support, not just on grounds of social justice, the needs of people with mental illness and their families, and human rights — and there are a number of strong arguments that we can use — but I also want to make the point that it makes economic sense. It is very wasteful not to provide housing support for people and to have them keep on coming through the system. We are talking about the mental health system and also about the prison system. The homelessness system, where you have people cycling in and out of homelessness, is all extremely expensive. There have been some very compelling studies done; one in Western Australia is currently being done by AHURI, but there are also some good studies that are very valuable from the US which show that if you cost the savings, the cost offsets of providing housing and support for people with mental health problems, the costs of providing that housing and support are actually minimal. You almost save as much money as you spend, if you get it right.

We know that the models are out there about how to do this, and they exist in Australia. They were started in Victoria. In Queensland and New South Wales there has been some cross-fertilisation of learning. The New South Wales and Queensland examples have been evaluated very rigorously, and we now know with a lot of confidence about what works, about what the key features are of providing housing and support for people with mental illness. It is not a problem of not knowing how to do this; it is a problem of political will. To sort of add to that, it is about lack of supply of housing and support. Often when we have discussions of this kind about what needs to happen in housing, we get bogged down in what the best model is: is it transitional, is it long term, is it this one or that one? You can get lost in the acronyms of all the different service types, but almost all of those problems can actually be reduced to lack of supply, so those arguments and discussions would just go away if the problem was resourced properly. Not only at a policy level but also at a practice level there are some real distortions happening with people — workers, advocates, families, people with mental health problem — trying to cope the best they can within a system that just is not working because of a lack of supply.

I will just make a few additional comments to some of those points. Housing support is particularly important to carers. Carers understand the importance of housing and support for the people they are caring for, and they understand that from their own experience. Living with a person with a mental illness sometimes may be a preferred option but it also may be an option that has been taken by the person with mental illness or the family because of a lack of other options. You do not have to be tremendously imaginative to imagine what some of those situations are like when they are not the desired situations and where people are just doing the best they can.

Also, if someone with a mental illness is not living at home with their family, carers are still involved. They may be supporting the person to hold onto their accommodation, subsidising them financially or picking up the pieces when it does not go right. Our mental health system is currently crisis driven and treatment orientated. There is a strong argument for saying that deinstitutionalisation did not cater adequately for the accommodation needs of people with mental
illness. Deinstitutionalisation is a good thing, but sometimes people overlook the fact that when people were in institutions not only did they have treatment and support but they were also provided with secure, long-term accommodation in many cases, and that just does not exist to a large enough extent in the community now. But that can and should happen.

Back to supply issues, people with mental illness experience particular disadvantages in accessing housing. You can run through the different options that are available to everyone in terms of accessing housing. Private sector housing is unaffordable. We are talking about people who may be on DSP or Newstart. Lots of people with mental health problems prefer and need to live on their own. There is an incredibly acute shortage of affordable housing for single people. Also, they are likely to need to live near services, family and public transport, quite often in inner city areas where affordability is particularly acute.

Public housing does prioritise people with support needs, including people with mental health problems, and again there is a shortage of accommodation for single people, but public housing has its problems. It has been underfunded over the last 10 years. Through well-intentioned targeting, public housing is for people with very high needs, so there is an increased stigma about living in public housing. It may not be the best environment for recovering from a mental illness if you live in such a situation. Community housing has got enormous potential in this area. There are housing organisations, some of which are now being registered as housing associations. They were set up to provide housing for people with disabilities and mental health problems. But there is a current policy difficulty which I think is serious here in that because of well-intentioned new policies by the state government to improve the supply of housing, in effect — the affordability of housing — housing associations are actually required to grow their wealth in their housing stock to provide more houses. What that means is there is some unintentional, I think, incentives for those housing associations to provide housing for people on higher incomes so that they can use the additional rent to improve their supply of housing stock.

What that means in effect is that people who are on the pension or have a disability or even forms of income support are no longer the target or the priority of those forms of housing. That is something that needs to be addressed. In the Victorian state budget for 2007–08, $300 million in additional money was given to community housing, which was fantastic news for everyone concerned at face value but none of that money has actually been targeted for people with mental health problems and, combined with this in-built disincentive for housing associations to actually provide that, that is important.

I mentioned before that there are actually good economic reasons for providing housing and I have talked about the cost offsets already. Even though the evidence base shows that stable housing is a prerequisite to recovering from mental illness, some studies even go as far as saying it is more important than treatment in terms of being a predictor of whether you recover from mental illness or not. That is debatable, but certainly as a prerequisite it is very difficult to recover from mental illness if your housing is not stable, yet so often, and this is still the case, mental health services and housing services are separated in terms of the service systems, in terms of the bureaucracies, and in terms of the way that government sees them. We are very hopeful that Victoria’s new mental health reform strategy, which is proposing a more cross-government, inter-departmental approach to mental illness, will actually have some effect and will help us get some good data, but it may also encourage much better links and action on this issue in terms of linking housing support and mental health treatment in a much more cohesive way.

The CHAIR — I am conscious of the time. If you could conclude, but do carry on.

Mr ILSLEY — I will make a couple of points about what suitable housing might be because there is a whole range of housing types and accommodation types that people with mental illness find themselves in — homeless sector, crisis accommodation, transitional accommodation, SRSs, parts of the rehabilitation sector, parts of the clinical sector — it is complex and confusing. There are often discussions about what sort of housing should be provided to people with mental...
health problems. Sometimes I feel in those discussions what is lost is that consumer choice is
actually the best indicator of what is going to succeed. In the same way as if you or I were going
to go into some housing, what would succeed if I am going to live in housing would be: where I
want to live and the sort of housing I want to live in, who I want to live with, and the support that I
need. It is no different, and I think sometimes these discussions can lose that, and that consumer
choice is a fantastic guide to what suitability is.

I have already mentioned some of the geographical considerations and I also want to, in terms of
housing design, caution about the temptation for housing providers and governments to be
seduced by large economies of scale in terms of efficiencies. Again, coming back to the *Age*
article on mental health today, just because things are not working as well as they should have
done since deinstitutionalisation does not mean that we need new institutions. We actually need to
learn from what has been occurring and improve the service system we have.

**Mrs Powell** — Thank you, Ben. That is a good move into what I want to ask. I notice
that you talk about the need for caution in the building of large-scale facilities. Given your
comment that we do not want to go back to what we had, there is some support through people
talking to the inquiry for maybe a larger facility of 30 or 40 beds with the appropriate staffing,
with the appropriate safeguards. Can you see that as something that would be beneficial, not to be
cost-effective but in fact to be able to give the residents a greater choice of socialisation, of being
able to move in the community, and perhaps support packages?

**Mr Ilesley** — It is a good question. Sometimes it is hard to know what consumer
choice means, if there are a limited number of choices and to what extent, if the choice is between
no housing or poor housing or unsustainable housing and any kind of housing, then I suppose that
is a kind of choice. If it is the choice of a person to stay in an environment like that, with people
who they know and also to live with people with similar needs to themselves, then that can be
respected but it has to be a real choice with options for people to be able to live on their own with
the kind of support that they need, and with the social supports and support to help them recover
to have the kind of life that they choose, which may be involved with mainstream activities rather
than mental-health specific ones.

Having said that, whenever you talk to people who are involved in the mental health system there
is always this pressing need that is expressed that there is currently a massive shortage of
high-quality, long-term, secure supported accommodation for people who may not recover
quickly from their mental illness. They may have associated psychiatric disabilities. That is not to
say that you put them in just a maintenance model in terms of giving them support to maintain
their housing. I think it is important to maintain that recovery focus so that people can always
develop and have goals in their lives and improve. Those in current models, SRSs and others of
this sort of scale, are just nowhere near being able to provide that in terms of the resources that
they have.

**Mr Noonan** — Thanks for your submission. You are a national body, so you will be
looking all over the country at this issue — particularly this week, I gather, being Carers Week.
Given the terms of our inquiry, we are able to look beyond our borders at models of support and
models of accommodation which might be considered best practice. I wonder whether you could
supply for the committee some views about where Victoria sits currently in this area of your
expertise, and whether or not the committee should be looking — and you reference a couple I
think in New South Wales and Queensland — beyond our borders within Australia or
internationally at some best practice models in consideration of our report and recommendations
to government?

**Ms Pierce** — Are you talking mental health or disability or both?

**Mr Noonan** — Given this is about supported accommodation for people with
disability or mental illness or both, it is very broad, so that is the question I put.
Mr ILSLEY — I am intending to say a little bit more about the housing and support program, which is the Victorian program that was started in 1992 and 1993 and actually led the way in terms of other states in Australia in providing housing support for people with mental illness, including people who had spent many years in institutions. There are some very good learnings from that program. It was highly successful and almost a victim of its own success, because when people with long-term psychiatric disabilities were in secure housing of their own with support, they actually got better and then needed less support. The problem then was that there was no turnover to provide housing support for other people, because there was not enough supply of housing to provide replacement stock. That program has not grown. It was already fairly small — 70 or 80, I think, when it first started — but with better resourcing is actually a very good model. When it was set up it was not evaluated as thoroughly as the later examples that we have from Project 300 in Queensland and HASI in New South Wales. Those evaluations show very similar — —

Mr NOONAN — For the benefit of the committee you might talk briefly about those two, because we only know them by title rather than detail.

Mr ILSLEY — There are a couple of important principles that are not really complex. You need to provide long-term secure housing, so that can be through public housing or the housing associations that we mentioned before, and with a benevolent landlord who is independent of service provision in terms of treatment or support. You have got a home, you have got a benevolent landlord, you have got access to clinical treatment, and you have also got access and support from psychosocial support, which in Victoria is the PDRSS services — that is, the psychiatric disability rehabilitation and support services. The key to all of that working is that, with those different components, the jargon is to have them joined up, so they all have to be talking to each other. A landlord has to be able to have a relationship with the clinical services if they note that something is going wrong, or somebody with the support services or support and treatment services needs to be aware if something is going wrong in terms of the security of the housing and that sort of thing. When you have those things in place, you discover that people hold onto their housing, that they have reduced admissions to mental health services, physical health improves and there are a whole lot of outcomes. These are the kinds of cost offsets that I was referring to before. The model — the housing, the support — starts to pay for itself if you have those key features in place.

Ms PIERCE — And in disability, what can we say? It is clear that Victoria, I would say, is far more advanced than other states in deinstitutionalisation in disability and in having a network of community housing of a variety of sorts. I think access to supported accommodation proportionately is much better in Victoria. There is a whole history about why that is. That is a very good thing for us, but does not deny that there is still an accommodation crisis. I think in Victoria there are patches of brilliance in some of the models that are on the ground, like the notion of being an elite tenant for some people with disabilities, and notions like — what do you call that, Ben?

Mr ILSLEY — Cottage — —

Ms PIERCE — Living nearby, where you have people living in ordinary community housing supported by a person who lives in the same community and provides offsite support to them. Those sorts of models are very good and have great potential.

In terms of support for ageing parent carers, leaving aside the housing component, other states have far better developed — on a small scale — systems of supporting ageing families with issues like planning for the future and planning for transition, support with wills and estate planning and those sorts of things. We are dragging our feet in that area, despite the strong lobbying of the Network of Carer Associations.
Ms WOOLDRIDGE — I am very interested from the carers’ perspective in relation to what are the barriers to families being more involved in the treatment of their family member who has an mental illness or disability, and what might we do to shift what I think is in many cases embedded cultural practice to achieve a change so that families and carers can be more a partner in the process rather than not.

Mr ILSLEY — That is a very topical question in terms of mental health. This morning I was at a forum discussing a review of the Mental Health Act. There is very little in the Mental Health Act that actually supports involvement of carers in terms of the treatment of the person, their family member. That is a barrier. But there are also cultural barriers in terms of the way that service providers and professionals interpret the act, and also their imbedded practices. The mental health system that we have is very medically orientated. It uses a medical model which is all about the individual and their treatment. There are other countries that are much better at involving families and looking at the social context that people actually live in. I wish I knew the answer to the question. It is something that many people better than I have grappled with for many years.

We probably need to look at the way that professionals are taught in their institutions before they get out into the field. There is a whole lot of cultural and practice change that needs to happen once people are in the field. There may be accountability structures and even pricing of services in terms of the way that governments purchase services that could have some benefit here. For example, in the psychosocial support area, services have to provide a certain number of hours of support but they only effectively get paid for working with the individual. Carers and family members do not count in terms of the work that they do. There is probably a number of avenues to address. We have a long way to go.

Ms PIERCE — And maybe it is worth saying that in the disability sector there is tension between the disability rights movement and issues to do with family carers. It is very difficult to unpack boundaries in that issue where of course people with disabilities where possible should have the right to self-determination in decision making and all that sort of stuff. When capacity is an issue, then the rights of the family become more important. I do not think the sector has teased that out. But we also have a Department of Human Services that is very geared to person-centred practice rather than what we think is more important — person and family-centred practice, where that is appropriate. Families are often shut out of decision making around the needs of their sons and daughters. Families often feel excluded from participating in decision making around the care and management of their son or daughter, even when they are in a residential facility. Those issues, in terms of care inclusive practice, need to be addressed across the board.

Ms HILLMAN — And if I can make one follow-up to that. Often practitioners will perceive the carer as another resource as opposed to being a person who also requires support and participation in that holistic approach to planning. I used to manage home and community care services in local government so I saw that quite a lot where it was a case of, ‘The carer can do this and this and this, and we will provide this and this and this’. It was not about, ‘This carer has needs as well’. So there is a very strong cultural change needed.

Mrs POWELL — Just very briefly, you mentioned lack of data. A number of people have told us about the lack of data and obviously that is on the disability support register as well. Would that not increase substantially if we include those people who probably do not know they should getting support, like the homeless, like the parent who is looking after the family member until they get older or pass away and there is a crisis? If we include those sorts of people it would become even more of a crisis then and would limit the options again because only so much money would be able to be put into the different sorts of packages, whether it is support in the home or the options of building bricks and mortar.

Ms PIERCE — I think if you just look at the area of ageing parent carers, and we cannot get access to information about how many of them are on the DSR but there are a number, we are aware that many of those families are really discouraged from registering their need for future
accommodation on the DSR. They have said, ‘We are not in crisis now. We want to manage as long as we can’. The DSR is not set up to allow them to say, ‘We do not need accommodation now but in the future we might’. That burgeoning area of need across the state has to be one of the highest priorities over the coming decades. There will be many carers who are not in a position to continue the care of their son or daughter and where transition accommodation is needed.

Mr ILSLEY — Just to add to that, I think you are absolutely right. There would be many, many hidden carer families where people with a mental illness are living at home as well as the groups you talked about who would be in the homeless sector and what have you. I am thinking in particular of people maybe from diverse ethnic backgrounds who may not know about other options or their values may provide barriers to accessing other services. There is a whole lot of hidden need as well.

In terms of that adding extra pressure on the public purse, I want to come back to this idea that I am very keen on which is the whole-of-government approach. If you go to the Office of Housing and say, ‘This is the enormous need that we have in terms of mental health’, of course it will say, ‘We cannot do that’. But if you look at it from the perspective of using those cost offsets and looking at the benefits to other areas, you have a mental health system that can actually start to function and provide more access and save money because it is getting the throughput that it needs. It will not work if you just limit it to those governmental silos. Similarly, you can take pressure off the justice system and you save millions or billions of dollars if you are providing enough housing and support to people in the community instead of putting them in prison. We have to have that cross-departmental approach.

The CHAIR — Thank you very much for your presentation.

Witnesses withdrew.