

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Geelong — 23 October 2008

Members

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Witnesses

Mr D. Starkey, chief executive officer;

Ms J. Porter, manager, mental health support branch, community living; and

Ms J. Pierce, manager, accommodation, respite & community support, Karingal Community Living;
and

Ms D. Leigh, parent carer of Karingal client.

The CHAIR — Welcome to the public hearing. All evidence taken at these hearings are 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 to make any changes as appropriate. I ask you to introduce yourselves individually, give a brief description of your organisation and make a verbal submission.

Mr STARKEY — Sure. I will make a start. I am Daryl Starkey, the chief executive officer of Karingal; I have been there for the past eight years. My team I have here today. On my left is Jacqui Pierce, who is the manager of ARC support, which is a special initiative of Karingal and funded by Karingal principally to help people with acquired brain injury in the area of accommodation, respite and community support. Dot Leigh is a parent of a child with an intellectual disability who attends Karingal. Dot is also the chair of the Geelong Parent Network, which is a group of parents and carers with various disability agencies in Geelong. Jenny Porter is the manager of our mental health support division, which is a more recent division of Karingal. Each of us will present for a few minutes. I guess they will introduce themselves more fully as we go along. Is that okay?

The CHAIR — Yes, that is fine.

Mr STARKEY — As you are probably aware, we put together a joint submission with Gateways, who are presenting after us. The general manager of our state-funded division, Robyn Bradshaw, was instrumental in putting that together, but unfortunately she is away on leave interstate and cannot join us today. Hopefully we can adequately cover the areas that we submitted on.

Karingal is a not-for-profit community organisation that has existed in Geelong for the past 55 years. We deliver a very wide range of disability services and aged and mental health services now, and also mainstream employment programs in the commonwealth arena. We have extensive experience in providing accommodation services and support services for accommodation. Our services cover the whole Barwon south-western region and include shared supported accommodation, independent living units and a range of in-home personal care and community access supports available to people with intellectual disability, physical disability, acquired brain injury and neurological conditions and people with a mental illness.

We have been providing accommodation services for the past 35 years of our existence, and currently we own, rent or manage 15 properties in Geelong, Colac and Warrnambool for around 70 people with disabilities. We believe having a safe, secure and supportive accommodation facility is an extremely important basic need for all people, let alone people with a disability or mental illness. However, we find that the grim reality is that many of our Karingal families can see no light at the end of the accommodation tunnel and are faced with the prospect of having to care for their son or daughter with a disability until they die.

Today I would like to just briefly highlight three of the issues that are in our submission. They are: the unmet demand in the south-western region for accommodation; the inadequacies of the Department of Human Services disability support register; and our issue with the Department of Human Services being a provider of shared supported accommodation. That is not to diminish the other issues we have raised in the report.

But I would like to share with you something that we have raised in our report, and that is an accommodation survey that Karingal undertook in March this year. We surveyed all of our coordinators — I think there are 8 to 10 of them — who are involved in providing staffing for people with disabilities in accommodation or their support services. We have around 1000 clients with disabilities in our region. We surveyed all of our staff in March this year in preparation for a

submission I was making to the Karingal board about the unmet need to try to highlight to them that Karingal should be spending money on accommodation facilities; principally that was the reason I did it.

We found in terms of estimated demand for accommodation and support services just over the next five years in our region for our families there were 101 people requiring shared support accommodation or 24-hour support. Half of those people — 50 — had ageing parents or carers. We also found that 36 people required housing and individual support packages to enable them to live independently — that was on top of the 101. The number of people we assessed in that survey who required immediate shared support accommodation or independent housing — who needed something done immediately — was 23. This was back in March. So we do have a lot more information available in our survey. It was done with our coordinators at Karingal, but we believe the situation has been honestly and accurately portrayed. That reinforces all of the other studies that have been undertaken.

The second area that we have significant concerns over is the disability support register. Currently the Department of Human Services has the decision-making responsibility to register applicants on the DSR, and we have a number of concerns with the lack of transparency — and I heard the last speaker talk about that as well — and also the independence of that decision-making process. I will just run through some of the points that I believe highlight those concerns.

There are no service users or community representatives included in the decision to register a request on the register, and there is no consultation on what the priority status of that person would be; it is really a closed shop, and we do not think that is transparent. Also there is no opportunity for families of people with disabilities to appeal, because they do not know what the priority status is of their son or daughter who is placed on that register. They do not know whether they have been given a high-status or a low-status priority or what — so there is no opportunity to appeal that. As we just heard before, people have to make a big song and dance to try to get things changed — or the provider of the service does.

Thirdly, the criteria for the priority status on the disability support register does not include homelessness or, as is more often the case, we find, 'hidden homeless'. We have defined that in our submission. 'The hidden homeless' covers people in supported residential services, respite placements — we have got quite a few — people who are living in motels, cabins and caravans, and people, both under and over 50 years of age, who are living in residential aged care.

The fourth point is that the demand management strategy used by the Department of Human Services puts up multiple barriers to gaining access to supported accommodation, and many families just give up. The whole system is just too hard, so many people are not even registered on the register or they just drop off. And because of that some of the families just leave their son or daughter in our respite accommodation, because they see that is the only way to get priority in a crisis-driven system. Finally, the disability support register only measures immediate need, so it does not promote or support long-term planning for accommodation needs; it is really just about what is happening now.

The third area that I would like to cover is the government being a provider of accommodation services or shared support accommodation — CRUs. The non-government sector, including the peak body, National Disability Services, of which I am a member of the state committee, believes that the Department of Human Services should progressively cease operating CRUs. It is simply a matter of cost. It is not about quality of care. Currently the percentage of clients in Department of Human Services accommodation is 54 per cent. The other 46 per cent are in the community sector or NGOs.

The cost of accommodating residents or clients in Department of Human Services accommodation is a staggering 35 per cent higher than what the community sector provides it for. One of the key reasons there is the much higher pay rates that exist in the system, but there are

other factors as well. In dollar terms, the costs that were tabled in Parliament in 2006 showed that NGOs were funded at \$68 000 per person per annum for shared support accommodation and DHS was funded at \$92 000 per person. In simple terms that means that if NGOs and the community sector were running all shared support accommodation — although we know it is probably not feasible for them to run it all — 35 per cent more clients could be accommodated. That is in terms of operating costs. I know there are capital costs as well, but in terms of the operating costs, day in day out 35 per cent more clients could be accommodated in shared support accommodation if the community sector were running it.

On top of that over the past four years we have seen the Department of Human Services accommodation receive a far greater allocation of capital funds than the non-government sector. Some of that is because of the outplacement of the Kew residents, but it seems that the capital was available to the government sector but not to the non-government sector. We know there are implications for industrial relations of changing DHS houses to non-government houses, but there could be a progressive move towards that. We have got Colanda in Colac with a likelihood of closing down or substantially downsizing, and probably those residents will go out into the region or elsewhere. We find it difficult to understand why those residents could not go into NGO accommodation, but I believe the state government has committed with the unions to those people going into DHS houses. It just does not make sense if the NGO sector can run it for a lot less. More clients could be accommodated in our accommodation rather than in government accommodation. So we would like to see, at a minimum, any new shared support accommodation being run by the non-government sector, and then progressively over time when opportunities arise, for DHS houses to be reduced, just as opportunities come up; we know it cannot happen straightaway.

That really concludes the points that I wanted to highlight, so I will pass on to the next speaker, Jenny, unless there are any questions.

The CHAIR — After the presentation we will ask some questions.

Ms PORTER — As Daryl pointed out earlier, I am the manager of Karingal's mental health support program. It is a relatively new program and a stand-alone service; we are just coming up to our 12-month birthday. We have, however, provided outreach support for people with a mental illness for the past 13 years as an organisation. I think one of the key things with this provision of outreach support is that we have not actually had any flow-through of clients. That is a fantastic thing because that means that our outreach is keeping people in their own homes or supporting people where they are. The only flow-through we have had has actually been people passing away or moving into another state or another area.

That has meant that for 13 years there has been upwards of about 75 individuals across Geelong and Colac receiving outreach support. That outreach support is actually not significant in the context of hours per week. Our clients are averaging two hours of outreach support a week, and that is keeping them primarily within their homes. We are supporting some people in SRS services, and we certainly acknowledge that the SRSs do need those levels of outreach support from a specialist mental health area. They are not set up to provide services to people with a mental illness primarily. The staff are often not equipped with the skills or qualifications to work with this highly specialised group of individuals.

We also are even providing outreach support to a lady who is in her 50s. She has been a long-term outreach resident living at home with her family. Her physical and medical support needs became so great that early this year she was admitted into an aged care nursing facility, and she is in her 50s. But we are still providing an outreach care service to her, so she is still getting some support within an aged care facility. That is not ideal by anyone's stretch of the imagination.

Some of the issues that have cropped up for us include a lack of continuing outreach support to enhance and support the mental health recovery goals. If we could expand on that outreach service

that we can provide, we could keep people in homes. I think that might be an example of the early intervention that you were perhaps alluding to earlier. I have another view of early intervention as not just intervening with younger people but intervening earlier in a service delivery system. If we were able to intervene to provide outreach support to people to remain in their homes, perhaps that would not create that burden in the homelessness area.

We often find that there is an inadequate ability to respond to the complex health care relating to an individual's diagnosis with staff within particular services. There is a lack of long-term planning to ensure a holistic and integrated approach. For people in SRSs, again, there are very minimal, if any, activities of community-based services. Not wanting to go over again some of the points that earlier speakers have raised, there simply is not the money for those people to do so.

One of the difficulties that we are also facing with our new service, our personal helps and mentors program, is for individuals who are coming to see us with housing and support issues. If they have been in and out of medical facilities, in and out of community care facilities, in and out of families' and friends' homes, and doing the couch surfing that others have referred to, they often do not have what we refer to as a rental history in order to enter into the common rental market.

Even if there is the support available to assist someone, it is very difficult for someone to demonstrate, 'I have a rental history. I am a stable renter in the market.' That is another one of the issues that our service is facing, actually finding normal rental that all the rest of us are finding more and more difficult to access. It is an even greater difficulty for them because they do not have the rental history and I am afraid to say there still is prejudice and bias against people with a mental illness.

Some of the other issues with people residing together in SRSs or other facilities relate to compatibility: putting a younger person — as previous speakers have alluded to — with a mental illness and perhaps dual disability, a dual diagnosis of drug and alcohol issues, with people who are frail and aged. It is not appropriate for either group.

I will touch briefly on dual disability. This is emerging for us as a real issue. We are finding that staff are not skilled or equipped to work with people with dual disabilities, and that may be someone with a mental illness who also has an intellectual disability and/or autism. This is a really highly specialised area, and we are finding that staff are not as skilled as we would like them to be. Certainly Karingal is making an effort to offer training for staff in that area. We are a training organisation and we try as much as possible to try and provide training to people in disability, aged care and mental health. But again, it is highly specialised and working one-on-one in the field either with people still residing in their homes, in special residential services or in other forms of accommodation, is becoming more of an issue, particularly with those people who have high and complex support needs. Again, the staff are not well paid.

Some of the solutions perhaps? We believe a range of accommodation types are required to span the continuum of care for our clients. We often look at a continuum of care. It may include long-term facilities — what are referred to as step-up and step-down facilities — and supported accommodation with different levels of assistance right through to general housing and the outreach or support to go with that. Thank you. I will pass on to Jacqui Pierce, the manager of ARC support.

Ms PIERCE — I am going to just about throw away everything I had originally written and talk about some other things. I would like to preface everything by saying that this is about all of us: anyone at any time can acquire a disability. We all hope we will not, but the reality is we are one car accident away, one assault away or one stroke away. To me, the solutions are reasonably easy, because the bottom line is that we need to create supported accommodation options that we would be pleased and proud to live in. If we preface everything we do around supported accommodation by looking at it through that set of eyes and walking in others' shoes, I think it is

easy for us to come up with the solutions we need. Across the board we need to be proactive and therefore preventative. It is the early intervention stuff that Jenny and others prior to us have spoken about, because unless we do that we are going to continue to operate in a reactive and crisis-driven system.

People need to be able to stay home if that is the choice they make. I do not think it should be a government directive or a government policy that that is what everyone needs to do, but where that choice is made people need to be supported to be able to do that. One of the options that I think people need to seriously consider is what we call shared-care or part-time care models. If you have got a young person with an acquired brain injury, or really any disability.

My area is mainly acquired brain injury, but I have worked in the disability services sector for the last 21 years. I must say I find it distressing that the stories I have heard today I was hearing 21 years ago. With dual disability, that Jenny has mentioned, intellectual disability and mental health were playing ping-pong with people's lives 21 years ago and they still are, and as a Victorian taxpayer I find that incredibly distressing.

Shared care/part-time care is a way forward. It means that a carer — family carers who are caring 24 hours a day, seven days a week — know that that burden of care will be reduced. They might put their family member into a shared supported accommodation or even a two-bedroom unit for three nights a week and have them home the other four. Part-time shared models are a way of the future, and we have to look really seriously at how we can make that work for families.

I need to say that the disability support register — and it is following up some of the stuff that Daryl is saying — is totally inadequate. In a civilised society I do not think any parent should be forced to relinquish care. Again, 21 years ago I was actually helping parents relinquish care, not because I wanted to, but because we knew that was the only way to get a response from the service system. Again, it is distressing that 21 years on families are taking that same path to get action. The disability support register is forcing people still down that path.

We need to talk about lifetime supports. We need to get away from this whole episodic approach that we have — the in/out case management systems that we have. People's disabilities will not go away; they will need lifetime support, so we need to look at service models, as well as the bricks and mortar around what type of facilities to build. What are the support models that need to be in those facilities to make them right.

We need to ensure that services are as personalised as the people themselves. I am talking 'personalised' rather than 'individualised', because we are all interdependent — we are all human beings and we are not totally independent. We work in an interdependent way, but we need personalisation within that. I am not talking 'individualised', which, to me, often has more selfish connotations. It is about me as a person, what do I want and how would I want it to be delivered.

There was a question earlier about the Disability Services Act and whether people felt that meant we were moving forward. I think it does, but I think the rhetoric is not meeting reality yet. If I look specifically at people with acquired brain injury, they are now eligible under the Disability Support Act, since it was enacted in July 2007; however, their access to the support system that should be opening up for them is incredibly ad hoc. It depends on the region you live in in Victoria whether you get access or not. An example in this region is that people with acquired brain injury are not getting past the intake and response points. If they need case management, they are not getting past intake and response to get to case management. That is still very intellectual disability focused in this particular region, and hopefully that will change.

Some of the specific things that were in our paper were the inflexibility of current shared supported accommodation to respond to the needs of people with acquired and changing needs — young people with acquired brain injury and neurological conditions. This is often one of the triggers that puts them into nursing homes so we need to increase flexibility.

We need a continuum of options to be available in that area as personalised as the individuals themselves. That could be their own home with individual support packages, right through to shared support accommodation options. There is a need for active night support; sleepover support is often not adequate for those with high and complex support needs. There is a requirement for access to medically qualified staff within disability support services. That might mean what I call in-reach models from hospitals. If you have got somebody at home who needs medical access, get in-reach from your local hospitals put into those services. Transitional community accommodation facilities, live-in, slow-stream rehabilitation facilities are also needed in the area of acquired brain injury.

One of the other things that came up earlier was about the individual support packages. I would like to say that waiting for an individual support package is a bit like waiting for supported accommodation — you wait. They are finite, and once they have been allocated — if our region has allocated all of their ISPs for this year or whatever — they are gone. You literally have to wait for someone that has an ISP to die, or hopefully not need it any more if they have had appropriate rehabilitation and restoration, before you can get access to an ISP. Really it is just creating another whole waiting list for families, and I do not think we can say that is acceptable either. ISPs are definitely the way to go, but we need a whole lot more resources poured into that system. I will now hand over to Dot Leigh.

Ms LEIGH — I would like to start with some quotes from the Having a Say conference, which is an annual conference held for people with disabilities. One of its workshops is called ‘Dreams and aspirations’. It gives people the opportunity to talk about their goals and dreams for the future. I will read some of their goals and aspirations: to meet Jamie Oliver, to go to Disneyland, and to meet the cast of *Home and Away*. Now we come to the important ones: move out of home and live with some friends; my dream house — there was a picture of house and underneath that was written ‘being free and independent’; I wish for a house of my own; my dreams are to move out of house; my dream is moving house with x, y and z — three friends; living independently in my own unit in Oakleigh; to have better accommodation, and to live with my friends; and I agree with this one — have lots of money so I do not have to worry about anything any more. Not one person said, ‘I want to live with my family forever’, so I think that is getting it straight from the horse’s mouth.

The next heading I have called ‘Planning’. I can recall being involved with the 10-year plan; the state plan; IPPs, which were individual program plans; IEPs, which were individual educational plans; and GSPs, which were general service plans. Now we have PSPs, which are personal support plans, and PCPs, which are person-centred plans. Person-centred plans consider all aspects of the person’s life and all sources of available funding and support, including informal, formal and government sources. However, the most aspirational and detailed plans are of little value without the resources necessary to implement them. Terms like ‘support’ and ‘choice’ can be very misleading. This initiative promised much, but packages have been limited and not large enough to meet the needs of recipients. Choice is non-existent for supported, shared accommodation. Any vacancies that arise are filled by those in urgent need.

The next heading I have is ‘The process’. When I was originally compiling this I wrote ‘the department is invisible to families’; then I left it out, but I will put it back in again. The department is invisible. Families seeking accommodation do not know where to start. People understand the term ‘waiting list’ but not what is meant by the disability support register or what criteria is used for adding one’s name. As of June 2008, 1358 people are listed as needing shared, supported accommodation; they are actually on the register. The unmet need means that government-funded accommodation is crisis-driven and only available to people in urgent need. Then, if a placement is offered, it may be the only one available and not suited to the needs of the person requiring it.

Respite beds — I am repeating a lot of what is said, but it is so important that I think it bears repeating. Respite beds are often used for long periods until a vacancy occurs. While the special needs of aged carers must be acknowledged, the crisis-driven nature of the system means that

younger people eligible for services are denied their right to move out of home. The overwhelming concern for parent-carers is, 'What will happen to our sons and daughters when we are no longer able to care for them?'

My next heading is 'A home away from home'. While the disability sector has the role of providing a range of housing and support, one size does not fit all; it takes more than bricks and mortar to establish a real home. Some things that need to be considered are: the location — people should not be removed from their local community, they should be able to continue their family and personal relationships and retain formal and informal support. They need to be in proximity to their employment, their services, transport, shops and recreational activities.

Another consideration is the environment. Does the house fit into the streetscape? Is the exterior attractive and well maintained? What about the garden? Sometimes you can tell what a house is like by how the garden looks because nobody cares about it. The interior needs to be comfortable, well-equipped, clean and bright with adequate bedrooms, bathrooms, living areas and storage. There is a need for private as well as shared space, with rooms for personal possessions, hobbies and pets.

The staff ratio is important, and somebody mentioned active nights, which is really important in many cases. There is also a need for qualified staff with opportunities for professional development, as well as stable staff — allowing for relationships to develop. Sometimes staff come and go so quickly that they do not get to know the people they are caring for. Of course they also need to have a genuine concern about the wellbeing of residents.

Staff also need to have some home-making skills. They need to be able to cook a decent meal and do the laundry without putting jumpers, sheets and everything all in the one washing load and clothes coming out shrunken and dyed.

With respect to personal relationships, the ideal would be for them to share with friends or have some choice about persons with whom they live. Where this does not happen there is a need for compatibility of residents. There is a need for the family to be considered as partners who can make a valuable contribution. I was at a forum once on accommodation — I have attended quite a few forums and meetings about accommodation — and a young man who was working in a residence said something like, 'Once the person moves out of home, parents are no longer involved'.

We never cease to be parents; we are parents forever. People need the opportunity to maintain outside friendships and to continue to go to work, if that is what they are doing. They need to be able to attend their programs and to enjoy the leisure activities. The understanding that the success of living together depends on a team effort from staff and residents is very important.

I have put in another heading: 'Health, nutrition and grooming'. There is a need to balance the right to privacy and independence with supervision and monitoring of safety and health. Sometimes you just need to check whether somebody has tinea or rashes or dandruff, if they are rinsing their hair properly or something like that without invading their privacy, just to keep an eye on things. Nutrition and special diets need to be taken into account when shopping and in meal preparation. I am not sure what people ate before the invention of lasagne.

I can give one story about a girl on a special diet. Spaghetti was the meal for the night but she could not eat spaghetti because she was on a gluten-free diet. Of course the shopper had forgotten to purchase the special spaghetti so they put the spaghetti sauce onto a thing called a corn thin. I do not know if you have ever seen corn thins; they taste like cardboard; they are a sort of cross between cardboard and polystyrene. That was her tea for that night. I heard that from her mother who was quite distressed about it.

Clothing needs to be maintained and there should be a knowledge of ownership. We do not want clothes put into a pool where it is 'first in, best dressed'. It needs to be age appropriate, fashionable

and appropriate to the occasion and the weather. It took years for me to get my daughter to understand that you do not wear sandals and shorts in 5 degree temperatures.

Another story I heard from a parent was that a girl, who was in a wheelchair, arrived at her day program with a coat on — it was a cold day — and when she took the coat off she had pyjamas on. Somebody would have needed to help her dress because she was very disabled. Little things like this are not terribly important in the whole scheme of things, but they are important in a person's life.

People with lower support needs living independently in the community can also be at risk. A young man was befriended by an overseas visitor who took him out to nightclubs and to play pokies and for meals. Then after the visitor returned to his overseas home it was discovered that \$7000 was missing from the young man's bank account. It was not picked up until it was too late to do anything about it. Somebody needs to just keep an eye on things.

Another young man was living on his own, getting very lonely. Once in a while at night he would go out to the hotel, drink a bit too much and get into fights, and he ended up in police custody on more than one occasion. On a lighter note is an anecdote about another young lass living on her own with support. Her ironing was mounting up so her case worker said to her, 'Why don't you iron while the soopies are on?' — she used to watch *Days of Our Lives*. Her mother went to visit one day and she was doing the ironing and then the ads came on and she put the iron down and sort of did a little dance and her mother said, 'Why are you doing that?' and she said, 'Well I only have to iron while the soopies are on'.

I am nearly finished. I have a few final thoughts. I do not think parent contributions are valued — whether they are financial or in terms of support — for example, in the case of a family who built a house next door for their son and then were penalised both by Centrelink and the tax department as being the owners of two properties. They were penalised for doing the right thing and supporting their son.

Aged-care is means tested. I am not saying that disability services should be means tested but if people have money, or are left money, they are perhaps willing to contribute. There is no easy or simple way to do this. I think this could be a way to perhaps have more accommodation places. A lot of parents sometimes feel that if they got together with other parents perhaps they could do something. It has been done in the past, but I do not think that is encouraged very much.

People complain that it is taxpayers' money. With the GST we are all paying tax now. People with disabilities are paying tax when they buy things like clothes and all that sort of stuff — so we are all taxpayers.

I just wrote down, after hearing what other people said, 'Once upon a time we did have a case manager with the department', and that was very convenient. You could ring up and ask things, and they were there to support you or answer questions. There is really nowhere to go for parents. We have support from Karingal and from services but there is no one-stop shop, really, for people, and if you do get a case manager and then you want something else later on, it will be a different person, so you are starting off all over again.

I will finish up by saying: we cannot change the direction of the wind, but we can adjust the sails.

The CHAIR — Thank you very much.

Mr NOONAN — Thank you all for your contribution and for your submission as well. Thank you also for introducing Jamie Oliver and Disneyland and *Home and Away* — we have had a kind of entertainment theme this morning!

We heard yesterday in terms of the government's role as a provider that in terms of social services government provides in a whole lot of areas — aged-care, health, housing — and in many

respects has set some benchmarks as a result of those provisions. I suppose my question goes back to you, Daryl, and how you would, in your model, safeguard the standards of — potentially in the longer term — purely private providers in this area, particularly where you are caring for completely dependent individuals in that arrangement.

Mr STARKEY — Sure. Anecdotally we believe the non-government sector provides at least equal, if not better, quality of service, but the problem is it is not able to be measured. We would endorse, as we put in our submission, some sort of accreditation system for shared support accommodation at a minimum, similar to what is in place for the aged-care sector. We run some aged-care so we know the strict standards — there are 44 accreditation standards that you have to run. So we are not daunted by the prospect of an accreditation system, and I know that statewide the Department of Human Services is doing some good work in establishing a quality framework. I am not sure how far off shared support accommodation is but it probably does not go as far as it could.

I do not think it matters if the government is running the accommodation or non-government organisations are running it; the quality of care issues can be exactly the same. We would like to see an accreditation system introduced for accommodation because, as we know in aged-care, things can go wrong and standards can suffer. I think anecdotally generally across the sector there is a pretty good standard but there are some issues and there are some individual providers that maybe do not provide as good a service as others — but that can go for the department as well. The department is better funded, though, than the non-government organisations, so that is a bit of a bone of contention as well.

Mr NOONAN — Just as a follow-up — we have had another submission which would suggest a national framework for accreditation and compliance — is that something that you are supportive of?

Mr STARKEY — We would be more than happy with a national framework. We would strongly endorse it, and we would like to be involved.

Mr NOONAN — Thanks.

Ms WOOLDRIDGE — There is a little bit about it in your submission but I would be interested to know about the reality of being a person with a disability or mental illness in regional or country Victoria versus metropolitan Melbourne, and what the practical differences are in terms of being able to access services, proximity, time lines — if you have a sense of how it is different in regional Victoria as opposed to the city?

Mr STARKEY — I do not think there are lot of differences in Geelong per se but in the more rural areas of the region obviously access is more difficult and people with disabilities are living a long way from their families or carers potentially — so distance is an issue. But in Geelong many of our clients tell us that they prefer the closeness of the service that we offer. I think there is more of a community feel. That applies everywhere I think in Australia but somewhere like Geelong has much more of a community feel about it — and Warrnambool for that matter, and Colac. I am not sure if any of the others — —

Ms PIERCE — I was just going to say that from the perspective of an acquired brain injury there is that issue of lack of access to specialist services in rural and regional Victoria. A lot of the stuff is Melbourne-based and even the so-called statewide services that are supposed to support people with ABI and their families on a statewide basis are incredibly Melbourne-centric — so that is another whole issue: how does the government fund statewide services?

If it is going to make them statewide and base them in Melbourne, they need to do a whole lot of rethinking of that. That is one of the downsides — the access to specialist services, but I think one of the upsides is what Daryl is alluding to, which is the sense of community. I worked in

Melbourne for the first 10 years of my life in disability services and have been in Geelong for the last 10. The sense of community often means that people are better supported, because you can end up developing communities that care more easily in small rural remote areas than you can in somewhere like Melbourne, because you can build a whole lot of informal supports around people.

So you end up with Joe the local shopkeeper being part of the community that cares for Meg who lives down the road, because he sees Meg every day when she comes to get her milk and things. There is that ability within rural and remote areas. I think that sometimes does not exist in the bigger places.

Ms PORTER — Could I just add, with regard to the distances that people have to travel, often that is not factored into funding, into costs. For example, if we are providing a service to someone in the Otways, it is not just the 60-odd kilometres it takes us to get there, it is the 1½ hours it takes us to get into the Otways to provide a service to somebody. That is actually not factored in.

If we are funded, which we are, to provide 2 hours of outreach a week to an individual, we are going to take up 3 hours in travel — that is to go from Geelong. Our nearest place would be Colac. We try as much as possible to hire staff within the local communities to decrease some of those issues, but we still have the issue of providing someone with a disability or a mental health issue in the Otways where they are near a staff member who is trained and skilled enough to meet their needs. They are actually having to travel from Colac into the Otways. It is not just the distance; it is actually the time it takes to get there.

Also, one of the issues that some of our staff are finding, too, is some of the pockets in the Otways still have black spots for mobile phones. For those people who are actually travelling, we provide an after-hours call service, 24 hours a day, seven days a week. So for staff who are called out at 2 o'clock in the morning and they are at risk of hitting a black spot with their mobile phone, that is a real issue for our staff. They do not know what they are finding — farming communities with dogs let loose; there are all sorts of safety issues for staff. That is not factored into any of the costings. We have to build that in when we are providing a service to an individual when we are looking at their needs.

Mr SCHEFFER — Could I just follow on from Mary, when you talk about Melbourne-centric: what do you mean by that? Do you mean that the services physically are Melbourne bound? You touched on cultural aspects. Could you just unpack that for us a bit?

Ms PIERCE — In acquired brain injury there has been a history of funding statewide services. They fund maybe the Royal Talbot to provide what is called CBDATS, which is the cognitive behavioural disorder treatment service. That is seen as a statewide service, but part of it is what Jenny was just alluding to. If you are in Mildura and you need access to the services that CBDATS provides, either you as a family have to traipse all the way down to CBDATS in Melbourne or CBDATS has to find within its funding the ability to go to you in Mildura.

What we found with the statewide service is they try to provide a whole lot of secondary consultation to local generic agencies, which is great — the theory of that is really good, and it is about empowering local services to respond to the needs. Rather than trying to do the primary consultation themselves, they take on a secondary consultation model. That does not work particularly effectively in a lot of cases, because unless the agencies they are trying to skill up at a local level have the commitment to people with acquired brain injury and want to make a difference et cetera, there is a lot of lip-service done.

The secondary consultation might happen, but it does not actually produce results on the ground for families. I think that the statewide initiative model of funding statewide services has some

merits, but it also has some disadvantages in terms of people not in Melbourne are not getting adequate service.

Mr SCHEFFER — So Melbourne would not go to that secondary level?

Ms PIERCE — They can and they do, but a big part of it is the travel. As I said, if you are in Mildura or Swan Hill or any of those really much more remote areas. Or even Otways or —

Ms PORTER — Dartmoor.

Ms PIERCE — Dartmoor, yes, or Terang, those services find it incredibly hard. Even though they are supposed to, they find it incredibly hard to service those people in those rural and remote areas.

Mr SCHEFFER — My actual question was to Daryl, and it was just to follow up from Mary's question. You said quite a bit about the register and you listed a number of issues that you had with it. What comes out of that is what it should be. I was wondering if you could set out for us how you think a proper register should work.

Mr STARKEY — Sorry, now or later?

Mr SCHEFFER — No, in your idea. If they are the range of good criticisms of it — which are fair enough; that is what we are here for — how do think a register should work?

Mr STARKEY — In principle a register should be there to register all needs of people with disabilities in that community, particularly in relation to accommodation. It is really just, as I said before, a closed shop, where it is not transparent. They need to involve both advocacy groups, provider groups, people with disabilities in that process. You would have to be a bit suspicious that it is just keeping people — —

Mr SCHEFFER — I understand the criticisms. You made them really clear before. I am just thinking, having made those criticisms — which I think we understand — —

Mr STARKEY — Having an open process is what I am — —

Mr SCHEFFER — How could that be? Could you unpack the details?

Mr STARKEY — There should be meetings on a regular basis, monthly or whatever, to assess that needs register and for all people to be placed on the register so that families are not even bothering to do it. There needs to be constant surveillance of who goes on and off the register and the priority status that it is given. None of us knows that priority status.

Mr SCHEFFER — Are you suggesting a register would be a publicly accessible document? How would people know? You were talking before about where families or an individual person might sit on the register?

Mr STARKEY — I am not sure if it should be publicly accessible, depending on the level of detail. I think individuals who are on that register, their families should see the priority status they have been given, so if they have been given a low status and they believe it should be higher, there is some mechanism for them to appeal that process.

Ms PIERCE — That would be quite simple. That would be a letter to that family, saying, 'Fred has been placed on the register and has been given priority 1 for accommodation'. Families are not even getting that, so they have no idea.

Ms LEIGH — Families do not know whether they are on the register or not. It is a secret document.

Ms PIERCE — So a quite simple first step would be a letter out to families. But I think the other main issues that Daryl raised was that it is measuring that immediate need.

Mr SCHEFFER — Yes, that is right.

Ms PIERCE — It is not a long-term planning tool, which means we are never going to get out of crisis-driven responses, because we are not doing the planning for the future. I would like to see the DSR being able to be used for long-term planning processes.

Mr SCHEFFER — I take it just from your response that the criticisms, which are fair enough, are based on your experience, but you have not modelled what you think a good register should be and then tested the reality at the moment against your model. You have not gone through a rigorous process?

Mr STARKEY — We can certainly do that. We can certainly provide a detailed response if that is what is required. We said it to the Department of Human Services many times.

The CHAIR — Following on from Johan's question, not just you but even the previous witnesses mentioned the issues of parents ageing and that until they are aged or passed away, there is no provision in the register. The register does not identify it as a requirement. How do you think that should be managed? What would you like to see? How could the DHS manage the register to capture future needs, future demands?

Ms PIERCE — How can they do that?

The CHAIR — Yes.

Ms PIERCE — One of the ways around that is getting back to the case management that Dot referred to earlier. At the moment we have the in/out, open/close case management, so no-one has a really good, detailed knowledge of the individual person with a disability or their family's needs as those needs change. There needs to be a way of touching base with those families on a more regular basis. If someone is sitting on the DSR waiting for something to happen, either an ISP or shared supported accommodation, every three months or every two months someone should make contact with that family to see how that family is travelling.

'Do you still need to be on the DSR for this? Have your needs changed? Are there other issues we are not aware of?' need be asked. Unless the family gets into crisis and picks up the phone themselves and contacts DHS, or an advocacy agency on behalf of them picks up the phone, DHS has no awareness of the changing needs of that family and whether something is becoming more urgent or not.

The other issue is about aligning carer's ages with the person they are caring for — age as part of the long-term planning. On those DSRs you need to have a note of how old is Fred's mum and dad or Fred's sister or whoever it is that is caring for Fred.

Ms LEIGH — I am not sure about that.

Ms PIERCE — Because that needs to be a trigger. There should be some kind of alert that activates that Fred's carer has now hit 70, or Fred's carer has now hit 65. It does not have to be as specific as, 'She is 62 today'.

Ms LEIGH — Ninety!

Ms PIERCE — But something that automatically alerts. I would like to see some automatic alert systems built into the DSR that flag to people that something may be going on for those families.

Ms LEIGH — You might get a cake or a party!

Mr STARKEY — Can I just add that when Karingal did its survey back in March, we determined an estimated time line of when people would require housing. We broke it up into shared supported accommodation, but also accessible housing which does not require support. We broke the time line up into: what is immediately required, less than 2 years, 2 to 5 years, 5 to 10 years and greater than 10. Just to get that profile is a great start in trying to plan ahead. It just seems that nobody wants to know about it because it just exemplifies the urgency of more shared supported accommodation and other accessible housing options that are required.

The CHAIR — Dot, you mentioned about families getting together. A few of the previous witnesses in the last few days came up with some cluster home environments and arrangements.

Ms LEIGH — I do not actually mean cluster homes. I think they might start off okay but sometimes they end up like institutions which should not be on the agenda. Say four parents get together and maybe build a home, it is not the actual building that is the most difficult part, it is the support that it is perhaps needed. Noracomm (Northern Accommodation) was an organisation in the northern region some years ago — Jackie and I know one another from a past life — parents got together and formed an accommodation group and raised funds and wrote submissions and got funding and had some accommodation — I am not sure how many houses they had — and then at one stage all groups like that were defunded and so they lost their status.

I am not quite sure what actually happened to the homes. It has been done and there are parents who often say to other parents who know one another — and Geelong would be a good place for that to happen because it is a community and parents have got the wherewithal to share with other people, so it is one answer that could be — —

The CHAIR — What do you think the government's role or DHS's role should be in that situation?

Ms LEIGH — To help us. To show us how to do it.

The CHAIR — Support services, not the capital?

Ms LEIGH — Yes. Support services, not the capital.

Mr STARKEY — Not to fund the support services.

Ms LEIGH — Or we could also maybe do it through a service like Karingal or something. It is a contribution that I do not think is used widely enough, but I think it is there and there will be a lot of parents who would be willing to contribute financially.

Ms PIERCE — As long as we have got the rules right around shared equity and ownership and all those sorts of things — —

Ms LEIGH — Yes. It would have to be done legally and carefully and perhaps in partnership with another organisation.

Ms PIERCE — It also gives the person with a disability much more security over home ownership. They own a quarter or a half of it with whoever else is sharing with them, and that is actually really important in terms of long-term security.

Ms LEIGH — Yes.

Ms WOOLDRIDGE — Could I just follow on from that? The department says that that prioritises people who have access to money and can build a house over those who do not have access to money, and therefore they are not prepared to guarantee support associated with that. Can you think of a solution? Should people who can access that get the support over families and individuals who cannot? Or is there a solution to make that more equitable?

Ms PIERCE — I think we look at that as private health insurance versus public health.

Ms LEIGH — Yes. Or private schools.

Ms PIERCE — And what we do is say that where you implement that, you actually take the pressure off the public system.

Ms LEIGH — And you may free up other places for people who have not got their own finances.

Ms PIERCE — I think it is worth exploring in that context of private and public and how if we get two systems working well, in fact they end up assisting and supporting each other.

Ms LEIGH — Yes, and it might be few and far between, but every one person who can support themselves makes room for another person who cannot. Nobody should be denied access because they cannot afford it.

The CHAIR — Thank you very much for your presentation.

Witnesses withdrew.