

**FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE**

**Subcommittee**

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

Mildura — 6 November 2008

Members

Mr J. Perera

Mr W. Noonan

Mrs E. J. Powell

Mr J. Scheffer

Ms M. Wooldridge

Chair: Mr J. Perera

Staff

Research Officer: Dr T. Caulfield

Witnesses

Mr G. Ramm, general manager, and

Ms S. Hermans, planning and support services manager, Sunraysia Residential Services; and

Mr P. Herriman, carer.

**The CHAIR** — Welcome to the public hearing. To begin I should say that 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 we will provide a proof version of the transcript to each witness at the earliest opportunity. Please introduce yourself, give a brief description of your organisation and then make your submission.

**Ms HERMANS** — Thank you. Good morning, everyone. My name is Sue Hermans and I am the planning and support services manager at Sunraysia Residential Services here in Mildura. I have been working in Mildura in the disability sector for 19 years. I started a long time ago and I have worked for most of the agencies in Mildura within the disability sector, so I hope that I can offer some that experience to the committee, and I am completely honoured by the opportunity to do so today.

I would like to introduce George Ramm to you all. George is our general manager and also has a long history in support services and the delivery of services to individuals and families both here in Mildura and in other rural areas. It is also my humble privilege to introduce you all to Peter Herriman. Peter is an experienced family carer. Peter and I co-facilitate the ageing carers initiative support and planning group here in Mildura. The ageing carers initiative is a state government initiative — you guys are probably aware of it — designed to support mums and dads over the age of 65 to plan for the future when they are caring for someone with a significant disability, because they are an amazing group of people. That has been an absolute privilege.

We also want you to know that we endorse NDS's submission to your inquiry. We are a very active part of NDS. Our CEO, Marian Luehman, is very involved in numerous steering opportunities within NDS, so she is often shooting off the NDS information to us to read, but I know she has a passion as well. And she is on leave, so here we are!

I would also very much like to let you know that we consider ourselves to be here on behalf of our staffing group of 80 but also the 300-odd individuals and families who we provide support to in the Sunraysia area. We hope that we are able to do them justice today.

I need to let you know that Sunraysia Residential Services started 31 years ago. It was started by 14 people — family members and committed community members — who at that time opted not to send their children away to institutional care. SRS was built and put together by a group of families and community members right from the start. It continues to be governed to this day by a board on which we have family representation, staff representation and community member representation. I am terribly mindful that three or four of those people have been involved right from the start, including the manager of Centrelink, a local chemist and other family members — so it has a long history.

We would also like from the start to put to you that the complexity of the needs that we are being asked to meet has in the last two years increased dramatically. We see that it is linked to the ageing carer population — mums and dads who are seriously wanting to know what will happen to their loved ones when they are unable to continue in their caring role. We are also experiencing an increase in the number of families who are caring for people with serious behaviours of concern at home, under duress and under extraordinary pressure to continue in that caring role with limited respite and resources and limited opportunities to plan seriously for the future in terms of keeping their loved ones safe and keeping the integrity of the family relationship a happening and viable thing.

Sunraysia Residential Services has numerous arms. We do have a shared supported accommodation setting here in Mildura. It provides support to six individuals who have complicated needs and require 16-hour-plus-sleepover support, so we are a 24-hour service. We have an on-call service that is available to our staff in terms of backup and guidance. We support 28 individuals to live independently. Our definition of the term 'independently' is not requiring a sleepover. Those individuals can receive up to 8 hours a day of care if it is required.

The people we support have access to the state government's new individual support package — policy, should we call it? — or new way of doing business with the Department of Human Services. On a personal and professional level I embrace this opportunity to see people as individuals and not block-fund huge amounts of money that is not necessarily devoted to the needs of an individual once planning is completed. That brings up the issue of planning.

**Mr RAMM** — Do you want to mention respite?

**Ms HERMANS** — I do. We provide a respite service, so we have a facility that can be staffed 24 hours a day, depending on the needs of the people who have been booked in to stay. There are over 300 families that access our respite facility.

We have another house that Sunraysia Residential Services rents for opportunities when the respite facility is not the right environment for people, particularly if a person is displaying behaviours of concern that may put themselves or someone else at risk. We rent that property and staff it for those opportunities, to provide respite to the individuals and their families that require that break.

We have embraced the idea of the individualised support package model in terms of being able to set up a supported shared accommodation setting in response to a crisis for some families. We see that as possibly a way in the future of supported shared accommodation becoming more available in terms of seeing individuals with similar needs and being able to hopefully look at some compatibility issues and providing families with an opportunity to look at ongoing supports. The planning that goes into those situations is often crisis driven — that is the reality of it.

In terms of respite, we have seen an increasing number of families who assertively and heartbreakingly opt not to pick up their loved ones from respite. That is awful. It happened this week, and it is really quite emotional. The people tend to be families who are really quite typically developing, they are just running out of energy and are quite frustrated by the system in terms of getting ongoing supports and so take extreme measures for something to happen.

The model of planning for individuals is a wonderful philosophy. The resources required for plans to be rolled out as they were written needs to be very seriously discussed so that people have got an idea of limitations when they are planning for the future.

Sunraysia Residential Services also is involved with transition for Futures for Young Adults. That is for young people who are leaving the education system, if they have been involved with a specialist education system or if they have been in the mainstream system with aide support. Just recently, changes in the Futures for Young Adults program have included the introduction of the ISP model — the individual support package model — which is wonderful. No longer will families not be picked up as such, or there will not be the problem that we have had in the past where people with very high needs who have amazing families have gone under the radar until things fall over. We will actually be really aware of the needs of individuals right from the end of school, which is fantastic. It is very good.

I am aware that the early intervention model is also embracing individualised support packaging, which is fantastic as well. I have a passion for early intervention, after working here in early intervention for numerous years. Anecdotally, 70 per cent of the families could be you and I and our kids. They are high-functioning mums and dads that deserve respect and deserve an

opportunity to develop skills to plan well for the future. They are quite able to speak on behalf and assert for families who do not have those articulation skills.

We have invited those families recently to join the ageing carers initiative planning group. We are sort of throwing around the name the 'Sunraysia family network for planning'. We are hoping to provide an opportunity for the families of younger people to join with the development of skills for planning that the ageing carers initiatives has brought to Mildura.

What else do we do, George? We have an outside-school-hours program. It is pretty much open to everybody. It is literally after-school care, but we have a special welcoming mat for kids who have disabilities, because their families work, too, and it is very hard for those kids to be sometimes integrated into mainstream, outside-school-hours programs, depending on their needs.

We do have a population of young people with very high physical needs as well as severe intellectual disabilities — children who use wheelchairs to get around, who are PEG fed, with buttons in their tummies for their food and their nutritional consumption. They have ongoing, 24-hour supervision requirements, and their families are very weary.

We provide some intensive behaviour intervention for preschoolers, particularly preschoolers with low-functioning autism in terms of learning to learn again. We are very excited about the Helping Children with Autism packages that have been recently released by the commonwealth government. So we work in partnership with Mallee Family Care's early intervention service with those sorts of things, which is just great.

We also provide a program called Signposts, which is a program designed by the Parenting Research Centre, formerly the Victorian Parenting Centre, for the development of confidence and skills in parents who are caring for someone with a disability who displays difficult behaviour. Professionally and personally, I see this as the most extraordinary, proactive move that was ever funded by the Department of Human Services. At this point in time it is not funded. As an agency we continue to provide that service, because with professional support families can learn to manage difficult behaviour and become resilient, and they deserve that opportunity. I do not know who else I should say that to. I think I have said that to everybody.

What else do we do? Pretty much at the moment we embrace the act in terms of trying really hard to respond to the needs that come through the door. For the people who come to ask for assistance, sometimes it is just some help to think about planning and navigating the most complex system for families and trying to buffer families from the complexities or the maze at times. I think the Association for Children with a Disability put out a book called *Through the Maze*. I think that speaks a thousand words, because it is really complicated for families.

**Mr HERRIMAN** — Especially when the needs vary so much.

**Ms HERMANS** — They do; extraordinarily so. I will get back to what I wrote down. George very poignantly pointed out that there are really three points that we should try to get across clearly, because I am sure you hear lots and lots of words.

We sincerely believe that once a comprehensive, person-centred and family-sensitive plan has been completed, funds need to be allocated to those plans, not people left wondering whether their plans will actually come to fruition. I think it is healthy for the money to be invested somewhere safely by the government as such, but I think families need to have some kind of security in knowing that it is not going to be a crisis that is the trigger for their plans to be implemented. It would be fabulous if there were a clearly defined process for accessing that allocated fund once the family chose to retire from their caring role and not having to go to hospital themselves and having the social worker at the hospital trigger the plan.

The second point is that families as planning partners need and deserve to be educated and supported to develop the specific skills and confidence to plan well. Younger families will benefit

from engaging in the planning process as early as possible and from having an opportunity to experience success in planning. It will avoid some of the perils of the past where older families have been engaged in planning and things just have not worked out the way that they had planned. So they have extraordinarily negative experiences of planning in the past and are quite wary of any system that comes in bearing gifts. As a facilitator of people's plans, it is a very uncomfortable situation to be in when you have engaged in a planning process and then the systems do not seem to back up what you have been suggested to offer families.

The older carers situation at the moment is one of those prime examples in terms of the commonwealth and the state governments speaking clearly about money that is available for respite for the older carer population. The ageing carers initiative is the state government-funded — you guys would be aware of this stuff — and the older carers respite opportunities. It seems to have stalemated. I am sure there is someone really clever trying to figure that out, because it is making things very awkward on the ground for families and planners.

The third point is that different models need to be explored. Pretty much through Peter's point, every family is so different. Every individual with a disability is so extraordinarily unique, and every family system fluxes and changes. But when they actually make their plans, the idea is we would really love the idea of celebrating some successful models — things that are working. We would also like to embrace some of the mistakes of the past, have a bit of a really good talk about why things did not go well and what could be done differently to avoid those mistakes in the future, including de-funding things that are working well, which is really a very tragic thing.

This is a bit grandiose, but it is those creative ideas that could be encouraged, along with some healthy conversations to encourage families to actually think outside the models that are already available to come up with some creative solutions themselves — because they are quite capable. They are our three things. I will go into a bit of detail about some of that stuff. Do you want to say something?

**Mr RAMM** — No, you are doing fine.

**Ms HERMANS** — Planning is a real buzz word at the moment — 'planning for the future'. It requires a set of really quite professional skills to assist and engage a family to plan for the future. We believe that the families themselves are the best people to plan — high functioning mums and dads like Peter and his wife, and also the mums and dads who have got intellectual disabilities themselves. That population is growing and will grow exponentially over the next 20 years. There are mums and dads out there with their own learning difficulties who for some reason are not afforded the same level of planning. The planners who engage with those families need to understand the complexities of people with cognitive disabilities and present information in a more respectful way and not have conversations about or above them. Those families are really quite capable also of having dreams for the future for their young people who have got complicated situations, both developmentally and behaviourally.

I am terribly mindful of the increasing number of young people with disabilities becoming involved with the juvenile justice system, or Youth Justice. If you have a really good look, you will see that often those young people have mums and dads who have got learning difficulties themselves. We certainly believe that families are under stress, they are under extraordinary stress. You guys would be aware of that through NDS. There is all sorts of data to suggest that mums and dads are having difficulties with their own relationships.

Siblings Australia has put forward many papers about the stress that is placed on siblings when there is an expectation that brothers and sisters will pick up the caring role when mums and dads are unable to do those things. There is an extraordinary pressure also in terms of siblings being involved in financial administration after mum and dad become unable, often because they are looking after an ageing mum or dad and there is pressure to look after a brother or a sister with really complicated development. I think those siblings are a not-so-quiet population of people

actually; they speak up. We provide a level of support to siblings here in Mildura, and encourage them to be part of the planning process.

I made a point earlier about the vulnerability of the older mums and dads. They are from a very genteel generation which says thank you for everything that they get, and it is an absolute privilege to engage with them, but some of those mums and dads are just going to keep going until they fall over. That is their right. It makes it extraordinarily difficult in terms of promising that the system will pick up where they left off when they are unable to continue.

I would suggest that the population of mums and dads that is coming through from early intervention is my generation. We are young, we are 40. A lot of the mums and dads are both working and they have high expectations that the siblings of the kids with disabilities as well as the young person with a disability will go on and live meaningful lives. They are expecting that something will be available for the young people — in their early 20s, not in their 50s.

There is an expectation that those younger families engage in the planning process now and have some successes with that younger population of adults. When I started, the trendy words were 'normalisation' and 'social role valorisation'; all that is, is about people having the same opportunities to experience the community and the life that we do without even thinking. Yet it is a fallacy that the young population of 20 to 40-year-olds are afforded the opportunity to experience the things that we do. There are almost parallel universes created, as opposed to them joining in with regular community activities. That is one of the underlying themes I guess that we have been pushing in terms of our independent living support service — a joining-in program, in terms of encouraging young people to join back into extracurricular activities.

Often young people will head off to the specialist school system, for lots of different reasons, and I know lots of lovely people who go and teach there, but it is segregation. I know you guys are not looking into education, but it is an issue in terms of the lack of opportunity for typically developing children to have experiences of living and working and learning beside children who have got learning difficulties, so when those young people turn into adults they have not been afforded the opportunity to have relationships with people who have not got disabilities, and I see that as paramount. We have been working very hard in terms of encouraging the idea of young adults joining in again on a social level so that they can become real members of the community as they grow into adults.

I have got here 'Vulnerable people need to be protected'. They are the young people who live with families who do not have an expressive voice, who may not have the same opportunity to engage with services as families who are more articulate and more able to find out what is going on. Some families, where mum and dad, I guess, have the learning difficulties, miss out on things that other families who are more articulate can access. Sometimes it is a matter of the peer pressure that they experience when they engage with support groups. They are quite a different population of mums and dads that need to be cared for and looked after, because the ramification of not looking after that population is that there is an extraordinary need then for the person they are caring for to be looked after full time, not just in respite. They seem not to access a lot of services.

My next point around planning is that positive behaviour support skills are learnt, they are not inherent in our parenting skills. We had this conversation last night. I am quite passionate about this. Typically developing mums and dads need to learn skills to manage difficult behaviours that their typically developing children display. Families who are caring for young people with a learning difficulty as well experience that level of anxiety to a degree that if you have not walked in their shoes, you would not understand, in terms of the pressure from society and from their extended family, in terms of learning positive ways to increase skills and alternate behaviours for those young people. I see Signpost as an answer for that but there is a need for ongoing support, in terms of those families getting an opportunity to get together and talk about how they have managed things well.

The next heading I have got is 'Accommodation and support'. We believe that some continuity and transparency in the availability of accommodation and support is extraordinarily important. The ISP model we believe will start to actually address these issues in a much more transparent and much more continuous way. The idea is that the packages, or the needs of people, change and move with time, so that when there is a diagnosis very early, families are taught how to plan, and then when the accommodation support needs change down the track, they are actually able to self-effectuate and make their own choices and use the systems; the idea being that the less that we do, maybe the better the job that has been done earlier on, in terms of the confidence of families to plan for accommodation and support.

We believe that we really need to stop and celebrate the things that are working well. For some families the CRU model is what they want. They want their loved one to live in a supported accommodation environment with trained staff who choose to work there and who have ongoing professional development, and to live a happy, healthy life and to have meaningful relationships still with their families. There are obviously some families who are in a position financially to leave their house to their son or daughter, to offer up their home as an accommodation model and invite other people to come and live with them.

Peter is a living, breathing example of those families. He would like to leave his house to his daughter and invite other people to come and live with her. We are delving into the incredible legal requirements and red tape around an opportunity like that — as an ageing carer initiative. It will be a groundbreaking experience perhaps. It is about the maintenance of the property, obviously, and about the compatibility of people who might move in and live. So that is new, and it is pretty exciting.

There are other families who are actually happy to buy, rent or build properties for their sons and daughters to live in. They are just concerned about the supports being available to them if they go ahead and do those things, so there is a lot of planning to be done prior to those initiatives being launched. But there are families who would like to invest in bricks and mortar — they actually want to. They want to make sure that the neighbours are okay, because their sons and daughters are a very vulnerable population of people. Because they are on a disability support pension there is an assumption that public housing will be just fine, and it is not always the case. And I am very aware of some other models where people on low incomes will be encouraged to share and live together.

Some of the families we have talked to would very much like to be more active and in control, whether it be as a micro-board, in terms of who will actually be living next door to their son or daughter who has a learning difficulty and is really very vulnerable emotionally, physically and spiritually. Those mums and dads have dollars, and they want to be a little bit more in charge of the future in terms of where their young people reside.

**Mr HERRIMAN** — We also want some flexibility in that rule that 10 people make an institution as well. It seems to be an arbitrary figure, and there are certain synergies and things in having a larger community together who have centralised needs. We would like that rule to be a bit more flexible than it is at the moment. The rule, as you know, is that if 10 people are living together, that comes under the institution thing, which the government does not want to have anything to do with.

**Ms HERMANS** — I think about six weeks ago we were approached by local planning at the Department of Human Services in Bendigo about models that we would like to put forward, so we threw up all the models we could think of in terms of opportunities. One that we have talked about, and I know it is linked — and I am mindful of Doug — is building units together on the same block of land and having an opportunity for there to be someone with high needs living in one of the units which is fully staffed 24 hours a day, but there being four or five other units quite close by where maybe the families of the people who live there will buy those units and own them outright, and where those individuals would have access to the person at the front for overnight

support or to touch base with. They would have their individual packages, but one of the anxieties that lots of parents have is about who will be there at night-time. Who will be there to check to make sure things are okay? Who will shoo away people who might harm their son or daughter, and who will take some kind of caretaker role on the property? That is one of the models that we put forward, which would be all right.

**Mr HERRIMAN** — Yes. I think down on the peninsula they are looking along those lines at that sort of a model, aren't they?

**Ms HERMANS** — Yes, they are.

**Mr HERRIMAN** — But they are still stymied by the 10-person rule at the moment.

**Ms HERMANS** — Yes. I was approached by a younger family with an idea. We have got some retirement villages in Mildura — I am sure they are everywhere — and ours are The Vines and The Rose. Some of the younger families think that is a grand idea — communal living as such where people have their own units. We had that conversation about the possible stigma of lots of people with disabilities living together. I suppose what they are doing is weighing up the safety aspect versus the opportunities for the young people to still be part of the community but to be safe. It is not about buying a property 10 kilometres out of town with a fence around it; it is about buying property in the middle of town so that people can access the bus and they can access community venues, because the people we work with do not drive cars and it is very difficult for them to get around. It is about people having group accommodation and supported accommodation, and having access so they can be functioning and interested people in the community.

**Mr HERRIMAN** — If I can just say something about that. It is our plan at the moment to leave our house to our daughter and have her live there, but if there was a better alternative, we would certainly look at that as well — something like the units that Sue was talking about. But at the moment there is not any other practical alternative for us.

**Ms HERMANS** — As a non-government organisation we are in a pretty good position to try to be a bit creative and work in partnership with families and with Housing Choices Australia, which is what I believe they call themselves now, in terms of big property management. It was the Disability Housing Trust under Chris Glennan. We are having conversations with those people, because we are not property managers. Our CEO is pretty good at that sort of stuff — but on the ground we are support workers and practitioners and families are families, and they are not property managers. We are looking for someone to give us some very good advice about the possibility of families being more involved in property management and in the ownership of the properties where their sons and daughters live.

There is always going to be a population of vulnerable families who will never have the funds to be able to do that. We believe they should be included in those communities and not excluded in public housing, because I think then we are perpetuating their vulnerability. They deserve a protected environment as well, while being encouraged to do their own thing. The reality is that a lot of people require some guidance with their social skills, and if they are displaying behaviours of concern, people who are supporting them need to take some responsibility for allowing them to develop some skills to get the things they need in an alternative way.

I have made notes about what we are doing now. We have developed an arm of the organisation — this is on page 4. I have been all over the place with this.

**The CHAIR** — Do you want to keep going, or do you want us to ask some questions? Is it a long presentation?

**Ms HERMANS** — I could go on and on. The main point is that I really and sincerely believe that the more we engage with families and with the networks and supports they can

provide for each other, the better the system will be. They know what they want; I think they just need some confidence and support to be able to get those messages through to the people who hang onto the money. I think that is part of it. So there are Sunraysia families and there are planning partners, which is something we would like to promote. It is something we are doing, and we would like to encourage other rural communities to do that, because people know each other.

**The CHAIR** — Do you want to make some comments, Mr Ramm?

**Mr RAMM** — I am happy to answer questions, but probably just to summarise, there were a couple of points made about planning and referring it back to accommodation. I think the important thing for the new legislation around planning is the dialogue that is really starting to happen with families. Their immediate needs are coming out, but also there are some solutions to what the longer term needs are. If that information could be captured across a systemic level, there would be some chance of predicting the future.

I think one of the biggest problems — and it constantly amazes me — is that we have people who actually come out of the woodwork and who, through their own fault or perhaps because they are ageing, are presenting to the hospital or even to respite care and saying, ‘Help me’, and we have never heard of these people. They have managed to look after someone in the community without any engagement with any services in any shape or form. That is the ageing carers population. There are people out there we do not know about, but the ones out there we do know about have not been capturing the information systemically about what their immediate needs are and what their future needs will be.

Just on that as well, there seems to be a demographic that actually has done a great job for a long period looking after people in their community, and now that they are having a crisis, the only way they can get action is through presenting as a crisis. They are using that language, and they are doing things like leaving someone they have looked after for 40 or 50 years in respite and turning their back and walking away, because that is the only way they are getting action, whereas people who might, through generational issues, have left their child in hospital, are having their needs met, and the service system seems to cope with them. There is that crisis period that we are trying to deal with at the moment, but as I say, I honestly believe the future solution is engagement, and planning is a great way of engaging with families.

**Mr NOONAN** — Thank you for your extensive submission. If I go back to my notes, you talked about supporting 28 individuals who have taken up an individual package — I think I have that figure right?

**Ms HERMANS** — Yes, some of them have ISPs — individual support packages — that used to be called Support and Choice and Homes First until some smart person made them one. It was a grand idea. There are also some people who are supported by old block money, which is like a lump sum of money, but what we are doing internally is having internal ISPs using the same model and allocating.

**Mr NOONAN** — I suppose my question around those packages or that funding model is: what are the living arrangements for those 28 people? In answering that question, I would also be interested if you could go to what you said then about some using the individual packages to sort of set themselves up in a supported accommodation-type arrangement. You might just unpack that a little for us. The other first part, the 28 — —

**Ms HERMANS** — The individuals?

**Mr NOONAN** — Yes, their living arrangements and then talk about — if I have that right — how that came about.

**Ms HERMANS** — Yes, how people can actually combine their packages and create a supported accommodation setting. Up until recently there has been no conversation about actually building properties as such. We encourage people to rent their own properties. We encourage people to use housing services because they are on low incomes and they are entitled to put their name down for a unit. We have been fortunate in that because Mildura is a small town, we have been able to talk with housing services people here. When a property comes up in a similar area we try to give people an opportunity to not necessarily live together but live close so they can experience a sense of community, and live close by people they know. We have that happening in three courts at the moment.

In terms of people not necessarily living together, because not everyone wants to live with someone else and it is not always a good thing, if people can have housing services units close by and in close proximity to their friends, they can share supports. They can socialise together as well, but they can have support. We might physically come and visit you, but while I am visiting you, if someone else has a problem they can come and ask us. I will then come and see how you are going and help you with your ADLs — I think Barrie called them. We call them basic living skills: nutrition, budgeting, the basic things, keeping yourself healthy. People share those supports, primarily in housing services properties. Some people rent privately, but renting privately as an individual is extremely expensive, even if you can get full rent assistance. So we have a few people who share and who have been sharing for a long time, and that works really well. How many, George? Three or four groups of friends?

**Mr RAMM** — I should clarify it. It is based on the individual's needs and their request, so through the planning process they identified their circle of friends, their needs, their wants and their community — Mildura South, wherever they want to be — so it is based on that. Through that sometimes you can do the mapping process by saying, 'Here are two individuals who have very similar likes and wants', so sometimes we can match them up to that as well.

**Mr NOONAN** — So the 28 that you referred to in terms of the support, can you map across the 28 in terms of their living circumstances given that our inquiry is looking at the issue of accommodation in the main?

**Ms HERMANS** — Yes, those people do not require overnight support. That is the difference.

**Mr NOONAN** — Are they living with parents or friends?

**Ms HERMANS** — No, they are living in their own place.

**Mr NOONAN** — Independently, mainly?

**Ms HERMANS** — Sometimes with friends, yes. Through the planning process, if we identify some compatibilities between a couple of people, we introduce them to each other and give it a try. If it does not work out we find something else, but sometimes it works out really well. We have not got any more than two people living together. It is pretty much around relationship dynamics and people having space.

**Mr RAMM** — Just in regard to the accommodation as well, private rental is problematic. Discrimination — whatever you want to call it — is very hard unless really we can come in and guarantee in some way, shape or form that we will be there and maintain their investment. The other one is the private home. That is another big issue. They might be left in their home and over a period of time sometimes those houses just degenerate because the income is not there to maintain them. There is this wish by the families that this asset will last the lifetime of the individual, but the reality is that does not happen. There is usually a transition somewhere along the way, towards the end of the life of the home, where they move into public housing of some shape.

**Ms WOOLDRIDGE** — I would like to ask a question just on the last page, which you did not get to go through in detail, which is identifying serious systematic problems. There are two things here that I would like you to comment on. Firstly, we have talked a lot about the people you can house. We have not talked about the people that you cannot house. You have a comment here that there are no local facilities for people with complex needs and trying to maintain them in the community increases vulnerability and increases community services. While you are doing a fantastic job for the group you are delivering to, I would like to try to get a snapshot of the group that you are not. Secondly, the decisions that impact on local families, individuals and communities are made in Bendigo and Melbourne. As a regional community, what is the impact on you of being hours away from where decisions are made in respect of the provision of services?

**Ms HERMANS** — In relation to the first one, we have had conversations with people from MACNI — the Multiple and Complex Needs Initiative — in Melbourne. You would be aware of the criteria: a person with an intellectual disability, an acquired brain injury and mental health issues or a combination thereof. And in relation to the second one, a person who is at risk to themselves or to someone else. We actually support four people at the moment to meet that criteria and it is very difficult. It is really very hard. They do not have accommodation as such. We source private accommodation for them or we wait for someone who we are working with to move in somewhere else so we can move the puzzle around and offer them an opportunity of somewhere stable.

**Mr RAMM** — The issue is they present as a crisis as well. They will present to respite and it is a temporary facility where we have bookings from other families coming in so they cannot stay there long. There is no planning. They just present.

**Ms HERMANS** — But then we engage in planning very quickly and try to find something and find out who can help. I am very mindful that we have had some fabulous liaison with Barrie and his group for a couple of people who have an intellectual disability as well as mental health issues as well as an acquired brain injury. Those individuals use both services and we are looking at home-based support. They are providing day placement and the 4 hours a week. For some people I know we have had some conversations with the senior master about people who have had compensation and they are able to purchase their own services. We then investigate whether they can have ongoing TAC or an ISP. Often it is on the hop, trying to figure out where you can get ongoing services for people who have very complex development. But there is no place as such.

The shared supported accommodation service that we have actually replaced the original house that the families fundraised for. The families in the community got the house together out at Sunshine. The house that we have as shared supported accommodation replaced that because the original fell over and it was not worth maintaining. As an organisation there was lots of fundraising to have that come to fruition. We call it TICA — transition into community accommodation. The idea is for people to move in, for us to get a bit of an idea of what their needs are, compatibility, do some person-centred planning and then link them up with someone else to be able to move out into private accommodation. The reality is that it is such a great place to live, it is very hard to talk families into moving out. We have been successful recently with two people in terms of applying for individual support packages to allow them to move out and live safely in the community. But the idea of TICA for people with complicated development — maybe it fits with what mental health is asking for as well in terms of a safe space to just see what people can do for themselves and what sort of needs they really have instead of guessing. Like some really good assessments so that then people can be given supports that they need to move on into the community and rent privately with their supports.

**Mr RAMM** — The other thing is that the crisis-driven stuff is very hard to actually resource in terms of staff. We would have 700 hours a month of shifts that we have problems filling. The pool of people we call on, especially when there is a crisis, means we are pulling them

from those who are doing well and actually putting them into crisis management. Again, it is the logistics of dealing with crisis all the time. In effect I would suggest our organisations tend to be crisis driven and we are not being proactive. Some of those slower-type plans, those longer goals that people are trying to achieve, we are not getting to because we are just dealing with the crisis of the day-to-day stuff.

There are not those accommodation options and we are moving people when we should not be moving them.

**Ms WOOLDRIDGE** — And the remoteness of the decision making?

**Mr RAMM** — Remoteness in decision making?

**Ms HERMANS** — We get into the car and we go and make ourselves part of the decision-making people. As you are aware, Bendigo is our regional office; they are all the regional reference groups, and they are in Bendigo. The ageing carers initiative reference group is in Bendigo. George came to one, it was a bit of a talkfest. I go to the regional planning reference group once a month. You can be part of it but at the end of the day the panel which allocates individual support packages is Bendigo based, so it depends on what information we give them, really. They do not actually have relationships at all with the people who are asking for support.

**Mr RAMM** — It is hard to get people on the agenda for the decisions to be made and sometimes we tend to use the word ‘crisis’ a lot more often than we need to, just to get a hearing.

**Ms HERMANS** — I think the words are: ‘immediate’ and ‘urgent’. They are the words they are looking for when you ring 1800 783 783, which is the DHS intake; they hear the words ‘urgent’ and ‘immediate’ and heed; not ‘Can I have some help to plan for a fruitful future?’. And we know that the resources are limited, but I think it is linked. If a serious proactive approach is not put in place, we are just going to be crisis driven for ages and it is very unfair. People know what they want.

**The CHAIR** — Responding to the Mary’s question. You mentioned a model having individual units in the close proximity. In that model what are you recommending? Are parents or families prepared to contribute financially? Is that the model you are looking at?

**Ms HERMANS** — Some are, yes. Some are prepared to buy a unit for their own son or daughter and some of them are prepared to buy two other ones and rent them out to other people’s children if they cannot afford to buy their own. There is an opportunity for a serious family cooperative, but they want to be in on who lives there.

**The CHAIR** — Have you canvassed that situation before anywhere?

**Ms HERMANS** — Yes we put that forward, that was one; we were actually asked, which was excellent. It is the first time we have been asked in my humble 19-year history about, ‘What will we build? What do you think we should build?’. Hopefully that comes to fruition.

**Mr NOONAN** — Can I make an observation? Is that how you came together 31 years ago anyway? That model?

**Ms HERMANS** — Yes, family, yes!

**Mr NOONAN** — You have talked about planning a lot and right from the outset you talked about receiving some funding for some planning for the future for parents, particularly of carers over the age of 65. Can you talk about how that process is going, particularly in light of the fact that some of the people who are presenting currently, you are completely unaware of, or they just pop up having been carers for many decades? How is that process actually evolving, where are you at with it and what are you finding?

**Ms HERMANS** — Do you want to comment on that one?

**Mr HERRIMAN** — I will let you do that.

**Ms HERMANS** — We are finding that it is very, very difficult for families to trust the system, Wade. They have had difficulty in the past when they have put plans forward and they have not been followed through. They tend to just keep on keeping on sometimes until things get really bad. The ageing carers group fluctuates. We have got maybe eight people at maximum.

**Mr HERRIMAN** — Yes. Some people feel very insecure too, because they have been in that caring role all their lives almost and they are just a bit afraid of strangers coming in and interfering with what they are doing. They just sort of close their minds to the future, do not want to think about what is going to happen when they can no longer do it. They just keep soldiering on and no-one knows about them.

**Mr NOONAN** — What is the funding actually being used for? Are you coordinating that?

**Ms HERMANS** — That is a regional service, the ageing carers initiative. There is a coordinator through Bendigo Health Care Group.

**Mr RAMM** — Based in Castlemaine, which is 5 hours away!

**Ms HERMANS** — Yes, but Peggy visits, or she used to, but we have been encouraged to be self-sufficient with our funding, to become a group of families who chat and liaise with each other.

For the ageing carers initiative, the most recent regional reference group meeting was a couple of weeks ago. The idea of the ageing carers initiative now is really about engaging in planning with older carers, in getting concrete plans sorted out for how they would like things to look in the future. The funding is not really for ongoing respite. That really should convert now to an application for an individual support package for respite. Coming out of this new way of delivering services is actually some differentiation between what the different agencies are trying to do, which is very pleasing for planners in terms of buffering families from the big-picture changes within the department. Ageing carers really will be about planning, and ISPs will be about the supports and services that are delivered, which is good. It ebbs and flows and it is difficult to engage with families.

**Mr RAMM** — There are no resources there. There are very few resources for planning. I know the new legislation is very strong on planning. It is a great piece of legislation, but again the resources do not flow to actually enact the plan. I still believe some tokenistic planning is happening, and certainly I have seen it. Some mandated agencies will do something. They will do a phone plan. There is no engagement, there is no getting to know the family and their true beliefs and addressing some of these anxieties. I know in my time I have met families where the last person they spoke to from the government said, 'Trust me', but that was when they had had a child with a disability and they had said, 'Leave it here and if you take it home, it is on your head'. That was 50 years ago and they are still carrying the burden of those sort of statements.

**Ms HERMANS** — They are right. In the big picture it is the parents who chose not to send the kids away to care who are now disadvantaged.

**The CHAIR** — We are conscious of the time. Thank you very much for your presentation.

**Witnesses withdrew.**