

**FAMILY AND COMMUNITY
DEVELOPMENT COMMITTEE**

**MR J. PERERA MLA, Chair
MR W. NOONAN MLA, Member
MRS J. POWELL, Member**

**INQUIRY INTO SUPPORTED ACCOMMODATION
FOR VICTORIANS WITH A DISABILITY OR
MENTAL ILLNESS**

WITNESSES:

**REPRESENTING THE CARERS AND PARENTS SUPPORT GROUP,
BENALLA**

**MS SALLY MARTIN
MS BEV SCHULTZ
MS ELAINE WILLIAMS**

SHEPPARTON

10.26 AM, TUESDAY, 18 NOVEMBER 2008

THE CHAIR: Good morning, everybody. Welcome to the public hearing. My name is Jude Perera. I'm the chair of the Family and Community Development Committee which is conducting this inquiry. On my right is the Deputy Chair. I don't know whether I need to introduce her, she is your local member, Jeannette Powell, and on my left is Wade Noonan, Member for Williamstown?

MR NOONAN: Yes, that's right.

THE CHAIR: And on my extreme left is Dr Tanya Caulfield, research officer of the committee and to my extreme right is Bridget Noonan, assistant clerk of the Parliament. Now, the committee is looking into issues as you know, such as the standard, range and adequacy of care and accommodation currently available, the appropriateness of the current service providers, how unmet need is managed in Victoria, accessibility and appropriateness of accommodation for rural communities, ethnically diverse communities, indigenous Victorians and the impact of the current service provision on families and carers. The committee is an all-party investigatory committee of the Victorian Parliament and is due to report to the Parliament by 30 June next year after which the Government has up to six months to reply to the committee's report and recommendations.

All evidence taken at these hearings is protected by Parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Parliamentary Committees Act 2003, the Defamation Act 2005 and where applicable the provisions of reciprocal legislation in other Australian states and territories. Any comments a witness makes outside the hearing may not be afforded such privilege. So if you make a comment outside, you will not be afforded that privilege. We are recording the evidence and a proofed version of the transcript to each witness at the earliest opportunity. So I would invite Sally Martin - - -

MS MARTIN: Martin, yes.

THE CHAIR: - - - and your team first to introduce yourself for the Hansard and give a description of any organisation you represent and then make a verbal submission and after the submission we will follow up with questions, if any. All right.

MS MARTIN: Thank you. Thank you very much. Thank you for having us here today. Our carers and parents support group is based in Benalla and we probably have about 80-odd members and clients or carers and parents. I've got some information here. We've already made a submission to the inquiry so this is just a copy of that and also just some information so am I able to bring that up?

THE CHAIR: Yes.

MS MARTIN: And that will just give you some background on – we do – we're probably the only adult – we actually service families and carers of adult children with intellectual disabilities and we're probably the only support group in the Hume region but we do usually just do around Benalla, Numurkah, Myrtleford, Mansfield and we do have a client in Kilmore and basically we're here today just to say how, you know, it is a dire need for supported accommodation in the Hume region. We've just recently had a family that have left their autistic son in respite because they just

can't cope with him at home and there's no support for him – funding available for him at the minute although we've had something like 55 packages come into the region but they're all flexible packages. There's no vacancies in the supported accommodation for him.

We've recently had some different numbers quoted to us from DHS . One quote is that there is 70 to 80 people on the priority list for the DSR which is the disability support register and the other quote was 20 to 29 and of those 29 there was eight, at least, that were homeless and there was, I think – a smaller quote was that there was four to five vacancies in the region shared supported accom that were vacant due to the mix of clients because they can't put any other clients with these ones and the other quote was five to six vacancies within the Hume region so we can't sort of get a good look at what's actually happening.

But basically, I haven't really got much more to add to these. I have got – there's two others at the back. They've just been sent in this morning, one from another parent – two different parents so if you wanted any more information from them I could actually get them to speak to you at some stage later on. I don't know, you've obviously – did you want me to speak to this letter that we wrote?

MR NOONAN: It's probably worth just summarising it in your own words and also just introducing the other witnesses, if you can.

MS MARTIN: Sorry, beg your pardon.

MR NOONAN: Just for our Hansard as well.

MS MARTIN: Yes. This is Bev Schultz.

MR NOONAN: Bev.

MS SCHULTZ: Hello.

MS MARTIN: She's a parent and carer in Benalla and this is Elaine Williams, she's also a parent and carer in Benalla.

MR NOONAN: Thank you. So were you just going to - - -

MS MARTIN: Yes, go through that.

MR NOONAN: - - - work through this for us.

MS MARTIN: Basically we provide information, support and advocacy for parents. We have a small office in Benalla and many of our families live in rural and remote areas of North East Victoria and are bound by Myrtleford, Numurkah and Ruffy and Mansfield. Our office receives ongoing calls from many parents regarding the lack of available beds in shared support accom in Benalla, Wangaratta and Mansfield. Benalla and Wangaratta could easily fill at least a six-bed facility tomorrow if the requests were all supported by available funding. We believe there's too many sons

and daughters aged 45-plus with high support needs that are still residing at home with their now aging parents or parent.

It's inappropriate and unacceptable for these parents and carers in their sixties and seventies to provide ongoing care for people with high support needs on a day to day basis without any indication that their person will be settled into some permanent accommodation soon. Number 2 was the only choices available in Hume region was the general supported accommodation facility that has up to six beds or the other option is to use the flexible funding, the ISPs that have come in and put at least three interested people, with their funding, that would cover say 24-hour care supervision. However, the biggest disadvantage to that is that if one pulls out, what happens to the other two.

So there's a real need to investigate a broad range of other models. Our support group six years ago have done some work on other sort of accommodation that they could easily do. I've done myself, through my diploma, just done another housing option which is sort of like a lead tenancy so there's – and there's lots of other models that we haven't, I believe, researched properly in Victoria that could suit – because not everything suits everybody and it would be really good for some research to be done in those areas.

The quality of care for both people with a disability and mental illness largely depends on where these people live and the ethos and attitude of the agency providing the support. Residential units are, in general, understaffed, thereby severely limiting the provision of any genuine opportunities for people to trial a range of recreational activities to chose from and pursue in their leisure time with support. Support workers are often not properly trained to deal with people with behaviours of concern. This leads to serious safety issues for residents and workers. Support workers, we believe, are underpaid for the important work that they carry out.

Parents believe the staff should be well-respected as good workers and rewarded with an appropriate wage. Better wages and respect will increase the retention of workers who deliver best practice service for people with disabilities. Generally parents experience a negative response when taking the big step to access long-term supported accommodation, including information, planning and decision-making due to the current situation in Hume region. There are no vacancies within DHS and the non-Government run community residential units. In Benalla and Mansfield vacancies in supported accom rarely become available and Wangaratta as well.

If a vacancy comes up then it is quickly filled by people with a higher priority as many other DHS clients with disabilities are deemed homeless so that is sort of reflecting back to what I originally said about those numbers. Parents and carers, by their very nature, do care for their families and do not wish to relinquish the caring role but are often forced to due to ill health and the need to ensure the person, who is disabled and vulnerable, will be settled and cared for in a manner chosen by the parents before the parents die.

It is unacceptable that parents are often placed in patronising situations and negatively judged when making reasonable requests to register their 40-plus year old son or daughter to be assessed for a DSR so that they move out of home and build a life for

themselves. Parents who are aging, that are left to care for their adult with disabilities, become unwell due to the stress of not knowing what will happen to their son or daughter in their future accommodation. The implications for people with disabilities who are not deemed a high priority for supported accom mean that they must continue to live at home with ailing parents who are suffering from increased stressed or anxiety, not knowing what the future holds leading to severe health problems.

Financial capacities of families is also diminished due to the amount of care required, limiting parents' choice to pursue careers or paid employment, as their peers. Families of people with disabilities are often forced to rely on Centrelink payments and the welfare system to survive. The current provision of care in supported accom needs to be reviewed across the private and Government and community sector. Positives of the current situation is that some people with lower support needs, with the ISPs, are having their needs met so that these carers and parents can rest easier at night. The Uniting Care Goulburn North East has an excellent record as a non-Government supporting people – sorry, non-Government organisation supporting people to find appropriate accommodation. However, they do not provide direct care. The negatives of the current situation and approach in rural and regional Victoria include the crisis driven accommodation services.

DSR is a priority list not a waiting list therefore no capacity to gauge the future need and no real future plan for accommodation, no available support accom beds for people in need, rapid onset of ill health of aging parents and carers, lack of real recreational and activities for people already in supported accom, better quality of care, increased support and wages for workers, negative and judgmental attitudes when a family are making requests, more funding for better paid and trained support staff, lack of accountability of the non-Government organisations in the invoices to families.

Transport is a huge issue in rural areas due to the increase and tyranny of distances. There's no plan B for people who partner with the ISP packages if one chooses to leave the house. Nursing homes, what role will they play? A need for a balanced choice of accommodation options presented. This situation cannot continue. Not only is it inappropriate and unacceptable for people with disability, according to the Disability Act it contravenes the freedom and rights protected by the Charter of Human Rights and Responsibilities and we look forward to the report and outcomes of the inquiry.

MRS POWELL: Sally, you've answered a lot of the questions that we've actually got here because, obviously, you know the issues. Can I pick up on two issues that you've raised because obviously your carers actually speak to your organisation. One of them, you said, that there is a need to investigate other models and you've said that you actually have done a thesis on what sort of funding models or what sort of accommodation models. I guess, if we're looking for something to recommend to the Government, we've had the institutions that people have said don't work.

We're now on the smaller housing models, which obviously we don't have enough of and your concern about the training of the staff and being able to train staff. Do you see that there's an opportunity to have, maybe plus the housing, which others have

said to us, with maybe up to 12 clients with the service provision and the support given but to have them – more than the smaller houses, to house people in bigger areas or bigger centres.

MS MARTIN: Sometimes the concern is that they become mini institutions but I think there should be various models. I mean, I think there's more opportunity in Melbourne – there's some other accommodation happening in Melbourne, I'm not sure what, but I certainly believe that it just seems to be either you're independently living here or you're in a facility. So there definitely needs to be a bit more of a range of how accommodation options are offered but basically there's nothing there at the minute. Bev and Elaine could probably speak to you.

MS SCHULTZ: I don't see – my husband and I have talked a lot about this. We don't see the problem with a gated community for young – well, people with disabilities. They have that type of thing for elderly people, why can't there be such an accommodation place built for people with disabilities.

MS MARTIN: I think there needs to be choice and I think that's what – Elaine, what's your – for Sandra?

MS WILLIAMS: I've got nothing against what you suggested at all.

MS MARTIN: It's just that 24 hour care - I think the Government find it so difficult to pay for that 24 hour care but there needs to be – you know, it's sort of - you're only offered this opportunity or that and there must be a huge range in the middle somewhere because some of these people could transition on to independent living. Like there's some already in supported accom that probably need to be out in the – you know, living independently because their abilities, you know, would warrant that they could do that at some stage.

MS SCHULTZ: Apparently in Yarrawonga there was land donated by the community. The community raised a lot of money but when it came time to get started the Government wasn't prepared to put in its bit to go ahead with building. And the community have been all prepared to start this - - -

MS MARTIN: It's not bricks and mortars, it's the actual 24 hour care. The payment of that ongoing recurrent funding is just not there.

THE CHAIR: So what was the community going to donate? What were they prepared to donate?

MS SCHULTZ: The community?

THE CHAIR: Yes. Yes.

MS SCHULTZ: The community had already prepared – donated the land.

THE CHAIR: They have?

MS SCHULTZ: Yes.

THE CHAIR: Yes.

MS SCHULTZ: We learned this in a meeting recently.

MS MARTIN: I think they're prepared to build it but I'm not sure.

MS SCHULTZ: They had worked hard to raise money for an accommodation place.

THE CHAIR: Right.

MS SCHULTZ: Everything was in preparation but the Government wasn't prepared to do its bid to back - - -

THE CHAIR: How did you approach the Government? You went to the DHS? Did you go through the DHS, Department of Human Services? How did you approach the Government? Let me say - - -

MS MARTIN: It's not really our area.

MS SCHULTZ: It's not our area.

MS MARTIN: We're in Benalla.

THE CHAIR: Right.

MS SCHULTZ: We were told about this.

THE CHAIR: Okay.

MS MARTIN: That's sort of hearsay, I suppose because - - -

MS SCHULTZ: We were told – here, I have the accommodation - - -

DON: Excuse me, is this the Yarrowonga Mulwala respite house?

MS MARTIN: The respite, yes.

DON: That's not accommodation as such.

THE CHAIR: Excuse me. You're not supposed to make comments because this is the evidence we are getting from - - -

DON: Sorry.

MS MARTIN: Sorry.

THE CHAIR: That's all right.

MS MARTIN: He does actually know more than we do about that actual facility. That's Don from Numurkah.

THE CHAIR: Under my power – I don't know whether you are listed to give evidence later on?

DON: No, I'm not.

MS MARTIN: He can – I mean I'm certainly happy for him to speak about that facility. No? He is a parent.

MR NOONAN: We've got a listing of witnesses for the day and all this is recorded so - - -

MS MARTIN: Okay.

MS SCHULTZ: It's in here. Here. It was a respite house, I believe.

MRS POWELL: We would be happy to receive a submission or a letter just stating what - - -

MS MARTIN: I've got the information here.

MRS POWELL: What that issue was.

DON: I was just trying to add to the knowledge, that's all.

MR NOONAN: That's fine.

MS SCHULTZ: Funding for it's operation is not included in the department's future plan, so therefore the project is at a standstill.

MS MARTIN: I'm not sure about that. That was - - -

THE CHAIR: All right. That will be recorded.

MR NOONAN: We've probably got a bit of time for questions so we'll probably go back and forth a little bit if it's okay with you and, just to pick up on Jeanette's point, it is possible for people to make written submissions into the inquiry as well.

MS MARTIN: When do they close, please?

MR NOONAN: Well, I suppose the shorthand answer is as soon as possible because - - -

MRS POWELL: But we'll be flexible.

MR NOONAN: Yes, we are flexible but as soon as possible is because they have been open for quite a period of time.

MS MARTIN: Yes, I know, yes.

MRS POWELL: But we will – the submissions have closed but we will accept late submissions because the inquiry is actually bringing out a fair bit of information that we need.

MS MARTIN: That's good. Thank you.

MR NOONAN: I suppose, just as a follow on to Jeanette's question is the models, in particular, Sally that you've looked at and part of the inquiry's terms of reference is to look beyond our borders, I suppose, and look at best practice, not just in Australia but potentially around the world. You referenced the keyring model from England and you might, for the benefit of the committee, talk about your research into that and if you can pick up the positives and also, as a lead tenancy question, we've been presented with evidence from other parts of Victoria to this inquiry that parents in some way are interested in potentially making a capital contribution to the infrastructure built in certain circumstances.

You might just comment on both of those issues, if you can, and if I miss out on some information, I won't be looking for it, I'll just ask you to follow up, if that's all right.

MS MARTIN: Well, we actually can't use the Keyring name too much because I think it is copyrighted but it is a very interesting model that they are running in England so – this is one of my assessments I did for my diploma and we called it Open Doors Housing Option and it was basically to let people live on their own so that they had a choice. They had – had a choice in what type of unit or house, where they lived in the community and had flexible support from a local community support worker with suitable in-home support or personal care as required and it – this is my paper – just went on about what is actually here now so we've already covered that.

MR NOONAN: So in part, in essence, it's a bit like having - - -

MS MARTIN: Would you like a copy?

MR NOONAN: I'm happy to receive a copy. This was of your thesis?

MS MARTIN: This is part of it, yes.

MR NOONAN: Okay.

MS MARTIN: This other one is regarding – this is regarding aging care.

MRS POWELL: Thank you.

MS MARTIN: But – it's six years ago so there has been a fair bit of work done in the past.

MR NOONAN: So in essence the open doorways housing open - - -

MS MARTIN: It's more an independent sort of – as in, it's opposed to shared supported accom - - -

MR NOONAN: Okay. So it's closely mirrored to what we might be now calling independent support packages in Parliament?

MS MARTIN: Yes. That's what I've based it on. How we could make it work.

MR NOONAN: Okay. That's good. This committee will take the time to have a look at those documents, which is good.

MS MARTIN: Yes. But it's not for everyone though because - - -

MR NOONAN: Yes, appreciate that.

MS MARTIN: Yes. That is still – the disadvantage is - - -

MR NOONAN: Yes.

MS MARTIN: - - - if someone actually pulls out and their package goes with them what happens to the remaining two or three?

MR NOONAN: Have you got a solution to that scenario because you have identified the problem but - - -

MS MARTIN: A solution may be respite house but then you've already got people sitting in respite houses that need to be moved out that are in long-term care.

MR NOONAN: Right.

MS MARTIN: So we're only propagating that issue but, I mean, hopefully you're going to match them up with someone else that's going to come in with their package, if you know what I mean. I mean, DHS is in that situation right now because of that mix of clients. It's very difficult to get people to live together in a harmonious way. So are we just shifting the problem from DHS into the community? I wouldn't like to go down that road but we certainly need to research how we can make those flexible packages work for everyone, yes.

MR NOONAN: I've got another question on flexible packages so I will come back to that. Lead tenancy in a block of units, we've had a number of submissions as we've moved around about families, particularly with aging carers putting up a proposition, potentially, to put some of their own funds into a block of units or a facility which might be shared or might be independent living in a congregate sort of arrangement. Have you got a view about that?

MS MARTIN: We actually have one running in Benalla right now.

MR NOONAN: Yes.

MS MARTIN: But it's not a lead tenancy because there's no one actually in 24 hour care in – there is a house at the front and there is units at the back, I think. How many units at the back?

MS SCHULTZ: Say six.

MS MARTIN: Six units at the back and well, those six units, I think, are nearly filled now with people with intellectual disabilities. The house at the front has people – general public living in the front house but it is proposed that we use that as a – this is with Uniting Care, they've been doing the creative housing there. It's a really good initiative but they have the same trouble with getting the mix right too.

MR NOONAN: Who has funded the six units?

MS MARTIN: They were donated by Mr Cook - - -

MS SCHULTZ: Ms Cook.

MS MARTIN: Ms Cook.

MS SCHULTZ: A member of the Uniting Church.

MS MARTIN: To the Uniting Church.

MS SCHULTZ: Yes. Wasn't the Housing Commission involved in it too?

MS MARTIN: Somehow. I'm not sure. The Housing Commission actually run the maintenance and they do the rental so they're all rented through the Housing Commission. I just not sure how it works.

MR NOONAN: Is there any outreach services provided to the residents?

MS MARTIN: Yes. Through - the Uniting Care have their pastor or visiting service.

MR NOONAN: Okay.

MS SCHULTZ: Someone from Shepparton handles duty too.

MS MARTIN: They've actually – all those people that are in the units have a varying degree of ISPs.

MR NOONAN: Okay.

MS MARTIN: And they have their own agencies that come in to do personal care and/or community living skills.

MS SCHULTZ: Judy has two workers.

MS MARTIN: Yes.

MR NOONAN: Is that – and this is, I promise this is the last question I'll ask in sequence – is this a model that you could see potentially parents might want to – because – to invest in because this has been donated but - - -

MS MARTIN: Well, I could see it working but that house at the front, that's our issue at the minute. If we could get three in there and have someone sleep overnight, then that could become that potential lead agency. The lead agency they do have overseas, they sometimes have volunteers do it and we don't recommend that because they have had trouble. Volunteers come and go and I don't think you have – you don't have as much, what's the word, don't have enough control to make sure that that supervision is being done.

MR NOONAN: That happens in Canada, doesn't it? That's a Canadian - - -

MS MARTIN: I thought it happened in the UK too.

MR NOONAN: Does it?

MS MARTIN: Yes. So I wouldn't like to see it go down that – the volunteer stuff, I think you actually have a paid lead tenant person there. I think they need to have that – well, just that – they're recognised for what they're doing and they need to be trained.

MR NOONAN: Thank you.

MRS POWELL: I have another question but I would just like to follow on from that one. The view of – I mean, there has been a number of members of the community that have come to me over time and suggested that maybe people can buy houses and make them available and then volunteers or parents or whoever can assist in looking after the adult children in the home. Is that the sort of model that you think might work – and, again, it would still be only about three or four children, adult children, in the house and that maybe they can use their packages to buy in the support they need or do you think it needs to be bigger than that?

I mean, I can see a community model that would be like that where the community would say a number of people would like to buy a house and perhaps make it available for three or four adult children so that the parents, the aging parents, know that their child is looked after and in a good place. Is that a model you think could work?

MS MARTIN: I think it falls down, that the community to pick up on things. I don't – you can't ask the community to do personal care. You have to pay someone.

MRS POWELL: I was actually thinking of the parents of the adult children.

MS MARTIN: But we may as well - a lot of the - - -

MS SCHULTZ: Are you talking about the parents helping to set up the house?

MRS POWELL: Yes.

MS SCHULTZ: And then getting paid workers to come in?

MRS POWELL: Yes.

MS SCHULTZ: Yes. My husband is keen on that idea. I keep saying that there's going to be too much fallback on us as parents.

MS MARTIN: Exactly, and that does happen already.

MS SCHULTZ: And I'm very worried about that, very concerned, but he said, you need to get the parents setting up the house. No, I can't see it working.

MS MARTIN: I also am a parent of a child with a disability who is living in an independent unit and they don't have a 24 hour lead agency there and even though he has probably the highest funding which you can get for an ISP the agency still tend to say, you know, when are you taking him home or – there is too much of that. I mean, families are getting older. Parents can't do it any more. They've done it. They done it for so many years that they need time out and they would like to go around and visit their son or daughter just as other people in the community do and certainly they want to make sure that they're well looked after but that – the responsibility needs to be shifted because that stress is ongoing and because – even where my son is, I still feel the stress of making sure – like I almost case manage it the whole time and so you've still got that pressure of making sure the agency is doing what is expected of them.

MS SCHULTZ: We talked to Anthony Putt at Central Access about this idea, Jeanette, and he put back onto my husband that my husband would have to do all the lobbying to get that sort of idea to work so therefore it falls back onto us again.

MRS POWELL: It was a model that was put forward to me a while ago where I think this is a group of people wanting to find an outcome and saying, well, we'll do something ourselves.

MS MARTIN: I think it should be a choice. If some parents want to do that then I think that that should be a choice for them.

MRS POWELL: Now, the question I wanted to ask was we talk about aging parents, do you think there is enough information that goes out to people who have a child with a mental illness or a disability to let them know the support packages that are available to them in their own home as they're growing up with the child and then as they age – because one of the issues that the committee have found is people are saying they can't get onto the register until there is a crisis, until the parent is almost having to go to hospital - - -

MS WILLIAMS: No.

MRS POWELL: - - - or has passed away and so we don't have that data of how much accommodation is needed because we don't know the extent of the problem.

MS MARTIN: Elaine could probably speak to that.

MS WILLIAMS: Yes. I filled in a submission to DHS for my daughter who is 42 who lives at home and – because in the past there was a register but they've done away with that now and I received a letter back from them that she wasn't – we

weren't in crisis. It was noted her need. So her name is somewhere now, where it wasn't before but there's no guarantee there is anything for her. So there's no package. There's nothing. I don't know how you get a package? How do you get a package? They talk about packages but you've got to be at a certain level. Not everyone is going to get package.

THE CHAIR: Do you know that there is a Disability Service Commissioner?

MS WILLIAMS: Yes, we do.

THE CHAIR: Have you made any complaints to him – his office?

MS WILLIAMS: But you have to go through a certain step before you reach him and some people are in that process, yes.

MS SCHULTZ: Sandra is going down that process now with her advocate for - - -

MS WILLIAMS: Yes. You just can't ring him up from that. You've got to go - - -

MS MARTIN: Because you actually have to go through the process - - -

MS WILLIAMS: Yes.

MS MARTIN: - - - DHS grievance process first before you actually go to the commissioner, so she's actually doing that.

THE CHAIR: You've done that. You've been – said before about the complex shape of the waiting list because you – you don't get enough information from DHS? Like waiting lists are distorted, is that right?

MS MARTIN: They don't – DHS don't hold waiting lists.

THE CHAIR: Yes.

MS MARTIN: It's against their policy to do that. It is DSR – it used to be the SNR, special needs register, and it used to be sort of a waiting list but their ideology is, that, you know, people could sit on that for years. We always thought it was for a planning tool but now they've done away with that now, they've got a disability support register and it seems that they do keep a bit of a list but, like, I would believe there's 70 to 80 on that list. I would believe that number would be correct for Hume region easily and a lot of people out there that haven't even bothered to go to DHS because they know there's no funding there for ongoing care and there's no vacancies and supported accommodation. So its quite a rigmarole, isn't it, Elaine?

MS WILLIAMS: It is a big rigmarole and it is very stressful. Really stressful as I've worded it.

MS MARTIN: And as I've said, people seem to have to actually be in total crisis. The family are unable to care for the son or daughter and that's the only way they'll

get supported accom. As I said, parents had to do it last week, had to leave their person in respite and not pick them up.

MS SCHULTZ: We did that once before. We were in total crisis and we left our child and because we did that, she was put into – she was taken off of us, what do you call that?

MS MARTIN: Ward of the State was she?

MS WILLIAMS: Custody of the department.

MS SCHULTZ: Yes.

MS WILLIAMS: Or foster care or something?

MS SCHULTZ: No. No.

MS MARTIN: How old was she?

MS SCHULTZ: It was about nine years ago.

MS MARTIN: So she was a child?

MS SCHULTZ: What do they call that when they - - -

MRS POWELL: Ward of the State.

MS MARTIN: Ward of the State.

MRS POWELL: Ward of the State.

MS SCHULTZ: Yes. And we had to fight the Family Court to get her back again because Human Services took her off us and it was all because we had really bad health problems that Human Services took her off us.

MS MARTIN: Family shouldn't be pushed to the extent that they have to do those sort of things.

MS SCHULTZ: And that was cruel. We've never gotten over that, that our daughter was taken off us.

MRS POWELL: One of the questions that we've been asking people who have got adult children with a disability or a mental illness is whether they think there should be more government supported accommodation or do you think there's a role for private accommodation or community accommodation?

MS MARTIN: I think there should be a range and I think there should be a choice. There should be different models out there that we can explore because nothing suits everyone.

MRS POWELL: Do you have a view of who is doing it better?

MS MARTIN: Well, I'd have to say that at the minute, DHS seem to be – have good quality service because they've got trained workers and their workers don't seem to be as stressed.

MS SCHULTZ: It's a matter of getting onto the right worker though because some of them hang up on you.

MS MARTIN: It depends on who is running the actual service and that is what it comes down to. The personality and the attitude and ethos of the person that heads that organisation filters down to all the workers and I think if you've got a really good person in charge, the service is excellent whereas if you've got someone that has a different agenda, such as a business or whatever, the dollar seems to run the business, then you lack some quality in your service provision. That's the sort of – what I see from outside.

MR NOONAN: We were actually in Mildura a couple of weeks ago and what struck me was the network, if you like, of different groups that are either supporting or providing direct services and I wonder whether you could – because we will hear from witnesses, both individual and groups today – I wonder whether you might just provide some comments to the committee about the number of organisations providing support or services in the region - I think you've mentioned the Hume region – and what are the positives and negatives of that network of organisations working across the region in terms of providing support to the group that we're looking at which are people with a mental illness or a disability.

MS MARTIN: Specifically accommodation?

MR NOONAN: Well, focus on accommodation but more broadly because accommodation can't necessarily work without a level of service or support. You can certainly link the two.

MS MARTIN: I can't speak for anything out of Hume because that's all I've dealt with is in Hume and it looks to me as – like I said, some non-Government organisations are excellent and some need to look more closely at their quality of provision of care to people with disabilities.

MR NOONAN: Can I get really specific? What makes an NGO excellent and what makes others in need of some level of improved standards?

MS MARTIN: Communication is a big one and I still go back to whoever runs – whoever is at the head, I think it filters down to all the others how they're respected as workers. You know, if people feel they're being supported and encouraged to work well and are paid, you know, a good rate and not the bare minimum, and the accountability of some organisations need to be looked into because a lot of families – I think I've quoted that in the letter – some accounts come out and even an accountant couldn't work out where exactly the funding was spent and I think – I'm hoping now that it's all changing over the ISPs that organisations will become more accountable and itemise their accounts so that you can actually sit down and see where those

dollars are going and why and, I mean, if you can understand them, then, you know, okay, that's fair enough but if you just get a bill for, you know, \$2000, you're thinking well, what about the funding that has come from DHS? Where has that gone?

MR NOONAN: So would you query whether or not all of the dollars are supposed to go to the people that - - -

MS MARTIN: I'm afraid I've had to, yes.

MR NOONAN: You've had to?

MS MARTIN: Yes.

MR NOONAN: Can you give any details of that? You don't have to name organisations but it is useful for the committee's deliberations to understand this.

MS MARTIN: I get really frustrated that I hear in some other towns and other places that their recreation – you know, the people there have a really broad range of opportunities and have lots of choice, which is great, it is exactly what they need whereas, I think, in Benalla we have one that – you know, the recreation is, I believe, segregated and isolates people and actually, I think – I believe some residents have actually become depressed because they haven't had a decent recreation program on weekend.

MR NOONAN: And you don't think that's through lack of funding. You just think that's through the way they operate?

MS MARTIN: Well, I just wonder – if other organisations can do it, then why can't it happen in Benalla.

MR NOONAN: Okay.

MS MARTIN: I don't run the business so I don't know. I don't know how the business runs.

THE CHAIR: But we feel that's nothing to do with funding. It's just that we're - - -

MS MARTIN: Well, we're told it is to do with funding. We're told that – when we question why is the recreation so limited, it's, “Oh, we don't get funding to do recreation” and like I said, when the ISPs come in maybe that may change and people will get a choice in what they do and maybe they will go out – I can still see them penny pinching, basically, and saying, “Oh, well, you know, you can only go out once a month or something like that” and I just think – my son has a huge social life and that's great for him but everyone should have that opportunity, not just my son.

MR NOONAN: Just one more follow up on that then. You said you queried – you queried; can you tell us what you queried, who you queried to and what the outcome of that query was?

MS MARTIN: Well, I've only just come into this job in February and we've had numerous meetings and I've just actually put in a – well, a complaint and I'm going down that complaint grievance process with this organisation and I intend to follow it through to the commissioner if I don't get the response people are happy with so it's actually a group – it's the members that have actually put in a complaint.

MR NOONAN: Okay. That's good.

MS MARTIN: So watch this space.

MR NOONAN: Thank you.

MRS POWELL: Can I just say that that follows on to the question I was going to ask, so thank you Wade.

MR NOONAN: That's all right.

MRS POWELL: You were saying before that some of your families were treated with a bit of disrespect and it causes stress. Is there somewhere – your organisation obviously supports the carers and the families. What do you do if somebody comes to you and says, I think my child is being neglected or not stimulated enough with recreation and things or they've been treated badly or spoken to badly or are not listening to any of the concerns, where do you take that complaint and is it dealt with?

MS MARTIN: Usually straight to the advocate, which is DAIS, Disability Advocacy and Information Service. I advocate for families so what I was referring to was actually parents get patronised when they're filling out, like, the DSR and also – yes, basically with - some agencies do patronise people so I was more talking about not actually people having neglect but if I had anyone come in and said – there's a couple of our families already going through that process of making sure with the advocate that their plan is being reviewed so that they do get some more recreation and the advocate will go to the commissioner if that's not responded to in an appropriate way.

MRS POWELL: So in that instance that's one line. The line where, if you're treated patronisingly by community or bureaucrats, is there a way of letting that organisation know so that they are retrained, if you like, on how to deal with people appropriately? It's a bit of customer service

MS MARTIN: Yes.

MRS POWELL: Is there a line down there that you can actually say to somebody
- - -

MS MARTIN: I was with the children's group and we actually run some – provide a service where we will go in and try and train people around respecting families' rights and, you know, look, families have done this for a long time and you could learn quite a lot. I think perhaps sometimes it's that defensive and power struggle that goes on that they do know more about the families so I'm a bit confronted. So sometimes it's a defence – do you know what I'm saying? It's a power struggle a little bit whereas

really you need to get down to the tints of what are we all here for? We're actually here for this person, not for the power. But, yes, it's very demeaning for families to be spoken to in a way - - -

MRS POWELL: And that needs to be stopped.

MS MARTIN: Definitely.

MRS POWELL: And there's a way of retraining those people and saying: the clients who you are dealing with are vulnerable anyway and under stress anyway.

MS MARTIN: That's right.

MRS POWELL: You're not to make it worse by treating them with disdain or - - -

MS MARTIN: Not all people. Look, there's some great people that work in the industry and they're wonderful and also our group have just been given – the new regional director is acknowledging carers and we've just been given some funding to do a carer's Hume project to heighten that awareness of – an acknowledgement of carers and parents and what they do and – which will be some forums and some focus groups and basically trying to get the older carers and any parents or whatever, to actually access more services because there is still a lack of information out there.

THE CHAIR: Finally, before we wind up, would you like to add any other recommendations? Do you have any?

MS SCHULTZ: Can I just say I don't see myself as an older parent. I'm not 50 yet but my daughter is only 22 but it is really because of health problems that my husband and I are both experiencing that we really, really need supported accommodation and it's just not happening and we've been wanting this for a year now and there's no – obviously no chance of getting it and it's very hard for us when we know that there is no vacancies out there when our health is getting worse, to know what we're going to do for our daughter. No one seems to be able to have any answers for us. How do we cope? How do we know what the future holds?

How do we help our youngest daughter who has health problems of her own as a typical teenager that is loaded down with stress-related problems and they're getting worse because of our stress-related problems. We don't seem to be able to help our youngest daughter because of all the problems that we're going through. I tell you what, it's awfully hard. The respite just isn't happening at the moment for us - not as much as we need because of all the blockages. The client mix and the overload in respite has made it so that I have to go out of town, out of Benalla to Wangaratta, to get respite and that's not fair.

THE CHAIR: All right. Thank you very much. All noted.

MR NOONAN: Thank you.

MS MARTIN: Would you like another copy of that and Bev's.

MR NOONAN: Yes, thank you.

MS WILLIAMS: Thank you.

MS SCHULTZ: Thank you.

MR NOONAN: Thanks very much.