

FAMILY AND COMMUNITY

5 **DEVELOPMENT COMMITTEE**

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MR J. PERRERA MLA, Chair
MR W. NOONAN MLA, Member
MR J. SCHEFFER MLA, Member
MRS J. POWELL, Member

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

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TRARALGON

9.09 AM, TUESDAY, 21 OCTOBER 2008

THE CHAIR: Good morning. I am Jude Perrera. I am the Chair of the Family and Community Development Committee which is conducting this inquiry and to my left is Deputy Chair of the Committee, Jeanette Powell, Member for Shepparton and to my right is Johan Scheffer, Member for Victoria East, eastern Victoria region which is part of this area and Wade Noonan is the Member for Williamstown; and also we have our executive officer Marcus Bromley. And we have come once again welcome to the public hearing of the Family and Community Development Committee which is inquiring into the provision of supported accommodation for Victorians with disability or mental illness.

The committee is looking into issues such as the standard range and adequacy of care and accommodation currently available, the appropriateness of the current service providers, how unmet need is managed in Victoria, accessibility and appropriateness of accommodation for rural communities, ethnically diverse communities, indigenous Victorians and the impact of the current service provision on families and carers. The committee is an all-party investigative committee of the Victorian Parliament, and is due to report to Parliament by 30 June next year, after which the government has up to six months to reply to the committee's report and recommendations.

All evidence taken at these hearings are protected by parliamentary privilege, as provided by the Constitution Act 1975, and further subject to the provisions of the Parliamentary Committees Act 2003, the Defamation Act 2005 and, where applicable, the provisions of political legislation in other Australian states and territories. Any comments a witness makes outside the hearing may not be afforded such privilege. We are recording the evidence and will provide a proofed version of the transcript to each witness at the earliest opportunity, so that it can be corrected as appropriate. So, I would like you to make a verbal submission or some opening comments, which will be followed by the questions.

MS JOHNSON: Okay. Firstly, do you know about Interchange? Would you like me to give you a brief description of Interchange, because that's who I represent today. But before I start, I'm not sure if you're all aware it's the launch of Carers Week, and this poster is going nationally across Australia. And it says:

Because I care. Caring for my son is the difference between an existence and a life. When I am no longer able to look after him, what will happen? It's not just food and shelter. He deserves a life rich in relationships, a good life, the same as everyone else.

And I think that's really appropriate to bring to this forum today.

THE CHAIR: Yes.

MS JOHNSON: Well, thank you for the opportunity to speak today. I am a volunteer family liaison officer with Interchange, as well as a member of the committee of management, and I speak to you today on behalf of 170 families across the Bass Coast, Baw Baw, South Gippsland and Latrobe. I also work for the Association for Children with a Disability, and I'm on the board of Carers Victoria

and vice president of Carers Australia. The background of Interchange, it's a not-for-profit organisation incorporated. It's governed by a voluntary committee of management elected annually by members. The aspiring community organisation provides much-needed respite, support to families who have a child or young person with a disability who live in those shires mentioned.

Parents provide all the love and care possible, but they often need breaks from the demands of care. We provide the support aimed at assisting families to cope with the demands and the isolation that they may feel as a result of providing full-time care for a child and a person with a disability. As we all know, the research shows planned respite can make a difference by giving parents and caregivers time off from their own needs. And respite within Interchange is given through a range of options, and its lots of choice of options, lots of flexibility, lots of social options. But from this information and these families we support, we also know there are issues in the supported accommodation.

So I'll just get straight into the issues. The current system is not responding at the same pace that the families need support. The support they often need might have been out of home respite, or in-home respite, supported community access for the child, intensive behaviour management support, or just a coordinated and planned response to their needs. The issues and recommendation Interchange would like to share with you today, on behalf of these families, are: families of children with a disability exist with separate and individual needs and have different resilience when it comes to the ongoing care of a child and young person with a disability or mental illness and their capacity to sustain that child within the family home.

We know families are dealing with an enormous array of emotions when having to consider supported accommodation for their precious child or young person with a disability. We recommend that families need a comprehensive range of supports to sustain them in their caring role. Recreational and respite support such as what Interchange is able to offer, and also various other models of support, such as consistent and regular access to out-of-home respite. This may alleviate the need for supported accommodation if that respite is given. At present, access to out-of-home overnight respite in Gippsland is in such high demand that many families will be lucky to access one weekend out of home in about three months.

That's probably being generous. There are very minimal beds. I can't quote the amount of beds, I'm sorry, but there are very minimal beds across our region for respite. And I know this is about supported accommodation, but I think if we take a step first in the respite side of it, it may reduce that really high need of the supported accommodation. We recommend investment into infrastructure and to build more community-based out-of-home respite options, as well as individualised and choices of styles of supported accommodation places for a person with a disability according to the need, the care- requirement and the style with which they choose to live.

They, as in the person with the disability, but often a person with a disability is unable to express their need, so therefore the family or the carer can step in and express their need. Personally, I have a 15 year old child with a severe profound disability. He is unable to speak. He's not able to say what he needs. I know his

care needs. I would like someone to listen to those care needs, and I would like the government to prepare this need. He's only 15. I'd love him to continue to live with me, but maybe there may come a time that that may not be possible. So there are children out there and young people who aren't able to provide their own wishes, but there are many that are able to give their own wishes of what they'd like.

All young adults should have the option to move out of home, and young adults with a disability should be supported to do so if they wish. This should be a part of life process, if this option is chosen, just like any other young person without a disability may choose to do when the time is right for either them personally, or their family, or their parents' circumstances change. We don't believe there should be large-scale housing developments that create segregation, but rather unique, individual accommodation options of varying styles and choices. Now, I'm not saying there shouldn't be cluster homes, because there are families who have created a network together.

As a family, you tend to lean towards other families who have a child with a disability because of the schooling and the recreation. You develop a support group together. Your children get to know each other. This is a perfect opportunity to gather them together, collaboratively talk, perhaps invest – if we have the funds, allow us the opportunity to put our funds together, draw from government funds, draw from community funds, and develop a cluster place of – you know, I heard you asking, wanting to know how many people – how many beds? You know, these could be all two-bedroom – 10 units together of two-bedroom, you know, in a courtyard that all comes out to each other.

And yet, there's perhaps a nurse that lives on-call, or there are carers. For example, my child needs 24/7 care, you can't leave him. So someone would have to be within the walls of where my child stays. So there's so many varying models that we need to look at, but it's all on an individual need, and we need to plan for these individual needs. Issues of families relinquishing care of their children. Continuous respite should not be used for long-term accommodation option. We need to allocate support according to the need. Children with severe challenging behaviours, where life must be just such an ongoing battle for family members and carers, must be addressed.

We must be strategic, and provide options that will be a win/win situation for all. Early intervention before crisis is required. Some of our families manage in the most trying and incredible circumstances to care for their child at home with minimal support. Some families may have resources that sound wonderful on paper, or in a care plan, and appear more than adequate to enable the family to cope, but even when this additional care and support is provided, often sometimes the family can no longer provide the care, for whatever reason. Sometimes it's the reason of a family – a parent can be threatened by the child or another family member.

I have – I'm working with families at this moment whose child is so challenging that they are actually attacking the other members of the family. So they have no other option but to choose to look at another alternative accommodation. We recommend that we need to all put our heads together, like we're obviously doing through this

inquiry. But we need to talk really closely with the families. We need to walk through their process and ask them what do they need, what do they want, what is their issue, and what would they like? And I'm sure you will get a collaboratively – a consistent response of people saying similar of what they would like.

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And that is, a place – there's many families that want to keep their child within their home. However, if they had one week's break, that that child lived out of home for a week, and in that week they got intensive behaviour support, they were taught how to control their behaviours, and then they came back in the home for a week, that would reduce costs for supported accommodation, but it would also provide respite to families, and it would also provide management strategies for the person with a disability. This is under the challenging behaviour factor. This is an absolute nightmare across the board. Many are in crisis. Many of these families are not bringing – picking up their children from respite, because they just can't possibly do it.

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So there's a really – a huge crisis out there. I don't know whether it's in the research, on the statistics, or whether the government are aware of it, but there is a huge crisis out there. Many parents suffer total exhaustion and extreme sleep deprivation after trying to meet demands of the care needs of children with complex health issues, multiple disabilities, and challenging behaviours. For those children with severe challenging behaviours – sorry. I'll start that one again. We – for the children with severe multiple disabilities and high medical needs, they need a place that they can be placed in a supported accommodation if the time was needed, where they are completely supported, monitored and provided with that 24/7 care the parent would give.

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A parent needs peace of mind to be able to know that when they do say it's time to look for a supported accommodation, that their child can be placed in a similar setting and a model to the Very Special Kids. This model is a perfect model for a child with severe high medical needs. I don't know whether you're aware of it, but I encourage the inquiry to look into it, because it is a beautiful, quality, one-on – almost one-on-one care for a child with high complex needs. And yes, it is highly – it does cost money, but it's something that's needed for these children or young people. And families need access to immediate service responses when their child has extremely – sorry, I'm going back to the violent behaviour side of it.

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Families need immediate responses when their child has extremely violent behaviours, because it impacts on the safety of other family members. There needs to be more BIST teams, which is the Behaviour Intervention Services Teams. Individual one-on-one workers are required to help with families, especially the families with the challenge behaviours or mental health issues, ie, the category of non-intellectual disability. Unfortunately, there's a lot of families out there, if their child doesn't have an intellectual disability, they are unable to access the service provision and supports. There is a model in the western region which I encourage the inquiry to view research, and that's a shared care model facility, where it is what I discussed, the seven days on of support and seven day – so seven days in the home, an seven days as supported accommodation.

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So it's a one – it is respite, yes, in one way, but it's ongoing, it's permanent. So it really is a form of supported accommodation. We recommend the duplication of this model across all regions. We believe allocation – a 50 per cent of future – allocate 50 per cent of future long-term social housing to people with a disability or mental illness, ensuring there is a quality framework in place, ensuring various housing options are available according to the need and the choice. Many families experience an overwhelming state of distress when they are finally in a position of in – and are unable to care for their child. Families love their child, and many have a strong wish and determination to remain involved in their child's life.

However, often it's with the deepest sadness and regret that they experience – that they have a diminished capacity to continue to care for the family member, for the child. The experience is heart wrenching and soul destroying for many carers. I dread the time that I'm not able to care for my child. What I would like to see is some supported accommodation to come into my home, to give me that support while I'm living with my child, so that I don't burn out, so that I don't become physically unwell. I think if we look at that model of supported accommodation in the home of the person, the carer, that's another model which would once again save government money but will allow me the opportunity to continue to love and care and be with my child.

That's just one model. Once again, it's a choice. There are a lot of families that don't want that choice. They want to go out – have their child go out into the community, and that's fair too. There needs to be more timely planning mechanisms in place for young people with a disability and their families and carers to enable opportunities to discuss and plan a choice of supported accommodation in the early years, not when it's about to happen. It needs to happen from when my child's 10 years old, perhaps someone come and visit me, talk – or visit a family, talk to them and say, "What can you afford? What's your ambition? What do you think your child would like to do?"

In this case, the child may not be able to make the decision, but let's start a collaborative approach, a sustainability approach, of what's needed out there, the capacity building of what we need to do. Another issue is when families are allocated a supported accommodation for their child. Often its miles and miles away from the family home, and the family neighbours, and the family members. This just does – isn't – it's not appropriate. Many families want to continue to be involved in these children's – young people's lives. However, when they're put 40 kilometres away from the family environment, it's just not possible to continue that connection. And how isolating it must be for a person with a disability and mental illness.

Mechanisms should be developed to allow combined government, family, private financial contributions towards the provision of housing and support for people with a disability and mental illness that does not adversely impact on eligibility to other disability funding. We need to gather connected families together, as I mentioned before. There is a model over in Canada called – in Toronto, the Takako model and they have actually gathered families together and actually built appropriate accommodation according to what they like. But they have also contributed to the families, but so have the Government contributed to it. And it's actually community

supported as well, with university students living there with free rent, etcetera, but they support the person with the disability.

5 So, that's just a model I thought I would mention. We urge Government to encourage and support innovative housing designs in all areas, physical buildings with modifications appropriate to the disability. We encourage the use of cluster models that may streamline the support. Access to adequate support to ensure residents can maintain their accommodation. I have been told that often the maintenance comes from family members and/or out of the pockets of the individual
10 or the housing accommodation is not maintained at all, so it does deteriorate. Housing designs that support culturally diverse, the families, who want to continue the care in their own home or within the surrounding of their own home.

15 Now, this isn't only just the Cole backgrounds but also for any – once again, it's a choice but I do – in my role with the Association and as well as some people within Gippsland, there are families who, under their religious beliefs, they do not want to give up their child or are not permitted in their own minds that they feel they should give up their child, therefore, I think we need to look at that granny flat system, the financial support to allow an alternative building to be put onto a home so that
20 there's a two bedroom facility attached to a house and a carer can come in and live with that person or support that person through the day. But they're still living within the environment of the family. I think that's really important. Once again, another choice.

25 Adequate resourcing to be made available throughout all the planning and implementation stages. We can't encourage this enough. We believe a person – a family should have a person to walk through the life for families, to walk through this process. Someone that can help families, in the early years, develop and establish a plan to look at what will work for them, and often it may change. But we
30 need planners. We used to have them. We need planners to come in and walk through with families. There needs to be much greater transparency in regard to how the allocation of a supported accommodation works. Interchange staff speak to many families who clearly do not know – the families clearly do not know about the process of the disability support register.

35 Many families thought they had their names down for supported accommodation only to find that some mechanisms, at some point, had determined that they did not meet the priority criteria and they had been bumped off the list. In some cases, they did not even know that they were off the list. I just continually say greater support to
40 families, wanting to look at flexible options such as finding care support with a group of friends who want to live together, shared accommodation. Sorry, I'm just going through this to find out – I have said a lot of this already. There also needs to be immediate increases in subsidy levels for home modifications and the development of a separate program that target home modifications for children with high support
45 needs.

If families were supported appropriately within their own homes with modifications, maybe once again supported accommodation may not be sought. One thing I would like to share with you, from a colleague of mine, and they have all said – she said:

5 *All individuals should have the right to live in a place called home, not
accommodation. the same rights as other individuals who live away from their
family, ie., to come and go as they please with support, if needed, the choice of
10 where and with whom they live and the type of home they might be, age
appropriate accommodation that is safe, accommodation standards of care,
appropriate staffing levels to ensure the safety of individuals in all forms of
shared supported accommodation, choice of accommodation, least restrictive
practices and be treated with dignity and respect, well trained permanent
15 workforce whose performance reviews are matched on salary rewards –*

because that is another issue with our supported accommodation. We don't have
consistent carers because the salary remuneration just is not acceptable.

15 *...an access to a range to transitional accommodation models for skill
development opportunities in preparation to move to more independent
accommodation.*

20 So, that is, let's develop supported accommodation in stages. Perhaps, you know,
where they are living together as a group and, you know, more carers that are helping
develop that independency and then eventually some may be able to move out into
the wider community, into a more independent. That's all I would like to say for
today.

25 THE CHAIR: Thank you.

MS JOHNSON: And sorry if I went over time.

30 MRS POWELL: Helen, I have been fortunate enough to hear your story about your
son, so I do know a bit of the background of what it's like being a parent of a child
with a severe disability. I guess listening to people today, as well as others that we
have heard, we have just realised how there's not one size fits all.

35 MS JOHNSON: Absolutely not.

40 MRS POWELL: And the complexity of the issues, with the disability and mental
illness, you raised a number of issues there about what you thought accommodation
choices would be and one of them was cluster houses and you gave us a model of
what you thought a cluster house would be. I guess one of the areas that I hear about
some of the cluster houses is even parents try to get into those houses and can't
because the child has certain challenging behaviours, whether it's violence or anti
social behaviours. So, it's actually slotting a child into the right cluster home so that
they fit in with the others that are there as well.

45 MS JOHNSON: Yes.

MRS POWELL: You also talked about the model at Toronto, which I would like
you to expand on that. Are they families that go into an area and you say they can
contribute, is it a family type of situation or?

MS JOHNSON: What it is, was a group of families that got together and they all had children with a similar disability but with the Government's collaboration approach, they actually built a – it was, like, multi story so it had lifts and everything.
5 So it was like a housing – a flat complex, I guess, but they were two children and they had a person with a disability but they also had a community person, being a university student who got free rent, who provided the overnight care, helped with some meals but then the people got personal carers through the day if some - for example, the community member – you know, this was their home too but they were
10 sharing it with a person with a disability. So, it wasn't - - -

MRS POWELL: So, it wasn't a family, it wasn't a whole family that moved into an area?

15 MS JOHNSON: No, no, no, no, no, no. No, it's totally independent.

MRS POWELL: Okay.

MS JOHNSON: Yes. Sorry.
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MRS POWELL: I just wanted to clear that up.

MS JOHNSON: Yes. I mean, once again, that's just a model that I'm just sharing with you because they came to Gippsland and spoke and, you know, it's an
25 interesting model.

MRS POWELL: And I guess the committee is open to all options - - -

MS JOHNSON: Yes, exactly.
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MRS POWELL: - - - because we're wanting to look at what the options are out there, because obviously there is some – one of the other issues that we have heard about is the issue of the need for different and perhaps more personalised support services. We also need to make sure that there isn't too many of one sort of support
35 service out there - - -

MS JOHNSON: Absolutely.

MRS POWELL: - - - and a lack of other sorts of support services out there. So we
40 need to be able to have a look at that as well.

MS JOHNSON: And I think you really – I mean, we're only speaking on behalf of families we know but there are so many families out there that once again have individual needs. And it may come to the crunch the Government do have to put
45 some people on the ground to go out there, visit these people and talk to them to create a – to be able to plan what we need to develop for the future. It's not going to happen overnight. We know that but it needs to happen and it's not going to happen if we don't address it. You know, there are so many families that aren't even on the

disability support register. So, that's an issue to me. I just think how is Government going to be able to plan and know if they're not – if they don't know about it?

5 We promote it within our organisation but we don't have a lot of families. There's so much – we have a waiting list of families in our organisation, however, we do try to tell them everything. This is just, you know, a small – we're just small though, in the rest of Victoria. So, it really needs to be looked at seriously across the whole State. Well, I say across the nation but anyway, we'll narrow it down to the State for the moment.

10 MRS POWELL: Little bits.

THE CHAIR: In the cluster home, are you proposing that there should be - funding should be shared by the families and the Government or should that be fully funded by the Government?

20 MS JOHNSON: I think the buildings should be funded by Government but I think if there's a capacity within the family to be able to do that – and I'm not encouraging that it should be that way, but there are some families who are fortunate to be able to do that. Let's give them the opportunity to contribute, let's ask them. If I was asked, for example, if – no, I won't say me. If some families were asked: Are they able to contribute to the ongoing care of their person in a supported accommodation?, Government may have the answer of yes.

25 So, we aren't asking that question. However, there are some families out there, they don't have a penny to put, you know, to put food on the table and so you cannot even look at the model or that question to those people. But let's get out there and ask. You know, there's some people that have a good family connection too, that may – if a standard pro forma document was developed and families were able to share that with relatives, friends, neighbours, there may a contribution that comes from that.

30 MRS POWELL: Can I just ask a clarification of that? A lot of older children, if you like, pay part of their pension, don't they when they go into supported accommodation. So is that the answer, where they get a pension and part of that pension goes towards the accommodation, so they in fact are contributing?

40 MS JOHNSON: Well, yes, but part – if you take part of a person's pension to be able to support them in accommodation, typical people work and can earn a really good income to help support them with their accommodation. However, a person with a disability, often has multitude of costs, of care costs. And I'm talking medication, continence, specialised food and equipment. Therefore, if you take part of their pension for some to go towards the accommodation, therefore, they're not able to sustain themselves. So, once again, it's an individual need. You know, if someone wants to contribute \$20 of their pension and they don't have all the other medical costs and everything, fine. I mean, that's all part of finance commitments, you know, that's all part of – it is part of living but I think once again it's an individual need.

Everyone needs to be looked at of an individual need. If you – my son turns – is 15. Once he's 16, he goes on a disability support pension. If I can't care and he has to move into supported accommodation, if you took a portion of his disability support pension, I mean, you'll be in the negative anyway, looking after him, because he's got huge costs. So, for equipment, continence products, medication, personal care. I mean, it's one on one care, so he will cost to the Government hundreds of thousands of dollars a year to be supported and yet I get a carer's allowance once a fortnight to do this. And he will – when he turns 16, he will get a disability support pension.

MR SCHEFFER: Just, look, thanks for that presentation, it was great. I think that if some Ministers of the Government were here, there wouldn't be a great deal – probably nothing that they would disagree with in your presentation. Right. So, taking your role in Carers Victoria and Carers Australia as well, and looking at the things that the Victorian Government has set in place - and remember we're, you know, going to put recommendations to the Government, so - - -

MS JOHNSON: Yes, which is fantastic.

MR SCHEFFER: - - - it's in our interests to know what you think.

MS JOHNSON: Yes, and I'm wrapt that it's happening.

MR SCHEFFER: But given that broad – those changes that have happened over the last few years, new Act, individualised plans - - -

MS JOHNSON: Victoria, we're talking.

MR SCHEFFER: Fairer Victoria, yes. A lot of investment in it, but we're still hearing what you're saying, what are the two or three things that you think are perhaps missing in that direction, do you think it's basically heading the right way but it needs a bit of tweaking or do you - - -

MS JOHNSON: Well, there's no buildings on the ground. There's no bricks and mortar at this moment to be able to – for families to even look at. So, it's all in imagination of what could be. We have nowhere to go to say, 'Well, you have this model, you have this model or you have this model'. Let's put some models on the ground so families can start looking at it, you know, and determining what is the right model. Or the people with a disability or mental illness look at it to determine, 'Is this the right model for me?' And if not, well maybe there needs to be an individualised model created. And that may be moving into a unit with this person that supports them.

MR SCHEFFER: So, you think – sorry to interrupt. You think that the structure if facing the right direction – I don't want to put words into your mouth.

MS JOHNSON: I think we are improving - - -

MR SCHEFFER: Okay.

MS JOHNSON: - - - as each year goes on. Not quick enough, I might say.

MR SCHEFFER: Right. So it needs to be sped up and there needs to be a lot more investment put into facilities.

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MS JOHNSON: Absolutely.

MR SCHEFFER: Models - - -

10 MS JOHNSON: Choices of facility. But once again – and I have to keep bringing my own personal situation. I don't want to put my son in a facility.

MR SCHEFFER: Sure. No, understood, yes.

15 MS JOHNSON: You know, I would like someone to come in and support the accommodation in my home so that I can leave my home. So there's so many different – you know, I know another person that would say, 'Don't you even suggest that'. So, you have another person sitting here, they would say something different. So, once again, we need Government to have people to ask the question
20 but we need Government to put the buildings on the ground - - -

MR SCHEFFER: Okay.

MS JOHNSON: - - - and the service provision on the ground to enable the choice.
25 You know, even – okay, you're an individual need, you have got a level of funding, okay, let's see what we can do with it. Or make a new level of funding, just look at what they need and provide it. But ask the family can they contribute too, because there may be that possibility. I would hate to ask a family member to help me out financially but if there was pro forma document available, maybe I would take it and
30 share it with my members of my family, rather than me use the words and ask the question.

MR SCHEFFER: Okay. Thanks.

35 MS JOHNSON: So.

MR NOONAN: Look, Helen, mine is a bit of a follow on to that, because you could be excused for thinking that supported accommodation is all about constructing lots of facilities around the place, but I interested just to explore with you further your
40 view about supported accommodation in the home, and understand from you, I suppose broadly, what support your family currently receives in terms of financial and otherwise, and what further resources you would require to deem your circumstances truly supported accommodation in the home.

45 MS JOHNSON: Yes.

MR NOONAN: I hope that makes sense.

MS JOHNSON: That's a great question, Wade, and I actually was with Kevin Rudd yesterday at the launch of carer's - - -

MR NOONAN: That was you was it?

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MS JOHNSON: Yes.

MR NOONAN: Yes, okay.

10 MS JOHNSON: And I actually said to him – I hate talking about my own personal situation because I'm here representing Interchange.

MR NOONAN: That's all right.

15 MS JOHNSON: However, I'll just take that hat off. I also support my 80 year old father. He lived with me as well. He's chronically ill, on full-time oxygen, and requires lots of personal care. He's – it's full on in my home. He has an EACH package, extended age care at home package, over \$45,000. It's a fantastic package. I can get all the support I need for Dad, and there's money left over still for when he
20 gets worse. He is much easier to care for than my father, and that's what I said to Kevin Rudd yesterday. Why is my father easier to care for by getting \$45,000 and my son has a linkages packages, even though I know that there's new individualised funding packages available now.

25 I haven't resourced that option yet, but I will be. But, at the moment, the linkages package, which has been around for a lot of years – so the individual support funding package has just come about, but I have had a \$5000 linkages package for a few years, okay. So that has helped support me with some respite within the home. However, I have also created my own network of respite workers. I pay them myself
30 as, you know – I might give them some petrol vouchers. I might take them away with me. We have a – my father still has his house on Roman Island. I might take them up there for a bit of a break, but they help me too, so that's the respite break.

35 So I work creatively. And I think if all families were given the idea of working creatively, maybe a precedent of stories, you know, offered to families, because many families have said what do you want. They don't know what they want because they're just trying to juggle with their every day. Let's give them some examples. But in my home I have some respite. I have developed my own support workers, and the linkages package, which isn't enough to support me. If I had more
40 funding, yeah, I would definitely be getting much more respite, but I don't. And I have a husband too who helps us. You know, I mean, he's my back bone. So I'm so lucky. Whereas there's so many families out there that are in single situations.

45 And, once again, the challenging behaviour is huge for those families who have a child with challenging behaviours. My son doesn't have a son challenging behaviour, but he has high medical needs and high physical needs.

MR NOONAN: So in terms of the respite in the home or the additional support, how many hours would you receive, and what do you think you might need in order

to, as I put it, sort of, deem your situation really supported accommodation in the home?

5 MS JOHNSON: Okay. I would – I mean, I would love to have a holiday. You know, I'd like to be able to take my husband away and go away for a good three week break to recharge the battery. However, because my son has high medical needs, requires daily enemas, is sick all the time, you know, it's hard to get the worker – a consistent worker or workers – to do that. So at the moment – I mean, I feel fortunate, and I feel terrible having to speak on behalf of me, but I have – okay,
10 what I believe everyone should get is according to the need and according to the situation.

When my son is really sick I need a break after he's well, and that doesn't happen. Now, I can't tell you now how often I need respite, because I don't know how often
15 he's going to get sick. But I think if every family, you know, got a good couple of weeks every third month, to me, that would be good. But supported accommodation – if I had someone coming bathing my son and giving him a daily enema, which takes an hour every night – the enema – that would be great supported accommodation in my mind. But I wouldn't even think to ask for that because I
20 don't think – I don't know, I just think - well, maybe there's going to be a day that I'll have to ask for that because I won't be able to physically do it.

MR NOONAN: But it could be as little as that?

25 MS JOHNSON: It could be as little as that. Every day have someone come in for three hours. You know, even someone to get him out of bed every morning or every second morning, because, you know, it's a full gamut of everything you have got to do. I don't know if you think about – we take it for granted what we do for ourselves to get ourselves ready, but when you're doing it for someone else as well, but right
30 down to the, you know, wiping the bottom every morning and cleaning and wiping their eyes, and cleaning the nose, and – you know, it's a huge gamut of what you have to do to support somebody.

And then feed them and then dress them. Make sure they're dressed and ready to
35 go, and make sure their bag is packed, make sure their food is packed, make sure they have got spare clothes. It's huge. So to give you – and my life is good, you know. So you have got someone else who can hardly get out of bed, suffering depression, financially strapped, and then still have to do all this. You know, I think they may need someone every day to do it. So, once again, it's an – I would not like
40 to say what would work because it's an individual need.

MR NOONAN: Sure.

45 MS JOHNSON: So every family will be different. And I wouldn't like to put on paper exactly what would work because I think every family is different, and I think some people may need that support full on every day.

MR NOONAN: Just with the indulgence of the chair, what did Kevin Rudd say to you in response then yesterday?

MS JOHNSON: He said, “We will look at it.” I said obviously we need more increase in budget, and I had Jenny Macklin ring me this morning - - -

5 MR NOONAN: Right.

MS JOHNSON: - - - because she’s actually speaking tonight at a social policy and she wants to put that into social policy about the development of looking – I actually spoke about looking at the household situation and looking at the needs. Don’t look
10 at the aged and, you know, the young, look at the need of the person and let’s provide the funding accordingly. And I don’t – I told him I don’t care where the money comes from, but it needs to come into the person’s life. So, you know, not them and us any more, let’s just look at the situation. And he gave me a kiss and he said, “I’ll look into it.”

15 So I must admit, I’m very – in a fortunate situation to also to speak of a situation that’s out there, so – but I’m not speaking on behalf of – I am representing people who are single. I don’t know how a mother or a father, individually, does this with a mountain of other children as well. It’s just huge.

20 MS JOHNSON: Look, it’s an interesting issue, the single parent household trying to support that arrangement. It’s probably an anecdotal response that you’ll give, but is there a disproportionate number of carers in single parent situations trying to support parents or children or partners with disabilities or mental illness in the home?

25 MS JOHNSON: You mean is it a high ratio?

MR NOONAN: Yes, that’s right.

30 MS JOHNSON: Absolutely. Very common that partners separate. I mean, you know, relationships are really hard to keep when you’re totally exhausted every day and you don’t – you know, you just can’t give someone else any time because you’re devoting your whole time to another person with either a disability or the challenging behaviours. I mean, I don’t know if you have ever read some stories from all the
35 carer’s books that are coming out about these challenging behaviours, but it is huge.

And today I’d like to present to you the challenging behaviour book of challenging behaviours, and there is a section on David’s story about supported accommodation. So I’d like to table that to give that to you to read about the different challenging
40 behaviours that families are dealing with. And a lot of these families child does not have an intellectual disability therefore they cannot access services according to the Department of Human Services – the Act – because they don’t have an intellectual disability.

45 You know, this is another issue in itself, which is the mental health side of it too. Many families can’t get services through the BIST team, the Behaviour Intervention Support Team, because their child doesn’t have an intellectual disability. So I’d like to table this booklet, and you may - - -

MR PERRERA: Thank you

5 MS JOHNSON: I can send you all a copy if you'd like one. But also the other one is the Coalition for Disability Rights got together. A group of organisations got together and wrote what they felt for the last election about supported accommodation. So I thought I'd like to share that with you – their recommendations as well, which we also support. So I have given you that as well.

10 MR PERRERA: Yes, thank you very much, Helen.

MS JOHNSON: No worries..

MR PERRERA: We'll take those documents as tabled.

15 MS JOHNSON: Yeah, no worries.

MR PERRERA: And we will conclude this session – this hearing.

20 MS JOHNSON: Yeah, I thank you very much for the opportunity on behalf of Interchange.

MR PERRERA: Thank you.

25 **MATTER ADJOURNED at 11.27 am INDEFINITELY**