FAMILY AND COMMUNITY
DEVELOPMENT COMMITTEE

MR J. PERRERA MLA, Chair
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INQUIRY INTO SUPPORTED ACCOMMODATION
FOR VICTORIANS WITH A DISABILITY OR
MENTAL ILLNESS

MS. J. TOPS
GIPPSLAND CARERS ASSOCIATION

MORWELL

1.00 PM, THURSDAY, 21 OCTOBER 2008
THE CHAIR: Good morning everybody. My name is Jude Perrera. I’m the Chair of the Family and Community Development Committee which is conducting this inquiry. First of all I would like to acknowledge our friend and our Parliamentary colleague, Member for Morwell, Russell Northe. Welcome. Thank you very much for coming along. To my left is the Deputy Chair of the Committee, Jeannette Powell, Member for Shepparton, and also to my right is the Member for Victoria East Region, Johan Scheffer, and also the Member for Williamstown, Wade Noonan, and also to my extreme right, Marcus Bromley, he is the Executive Officer of the Committee.

Now, once again welcome to the public hearing of the Community Development Committee inquiring into the provision of supported accommodation for Victorians with a disability or mental illness. The committee is looking into issues such as the standard, range and efficacy of care and accommodation currently available, the appropriateness of the current service providers, how unmet need is managed in Victoria, accessibility, appropriateness of accommodation for rural communities, particularly 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 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. We are recording the evidence and we will provide a proof version of the transcript to each witness at the earliest opportunity so that it can be corrected as appropriate.

Now, I have great pleasure in inviting Jean Tops, President of the Gippsland Care Association to make a verbal submission now, make some comments and after that will be followed by questions from the panel. Thank you.

MS J. TOPS: Thank you very much. We thank you for the opportunity to be here today and to make a presentation to the committee. Clearly for the carers of people with disabilities, handicapped, frailty, mental illness and indeed aging, this is a really, really vital hearing for us because, as you probably are already aware, families actually currently provide more than 93 per cent of all of the supported care accommodation in this state. So let me say that again. 93 per cent of all the supported accommodation in Victoria is currently provided by families. So, therefore, the dearth of services in disability accommodation and accommodation support fall most heavily on the families who are providing the care in the family home.

So our submission to you has concentrated very largely on the impact on families because of the failure of the disability accommodation support system in this state.

We have along the way made multiple submissions to inquiry after inquiry and one of the most critical of those - - -
THE CHAIR: Do you want to use the microphone?

MS TOPS: Sorry. I should be used to this really, shouldn’t I? Sorry about that. So one of the really, really critical issues is the constancy of the reviews, the inquiries and the hearings that take place year in and year out, decade after decade, and the most recent of those that have been very germane to what we’re talking about today, have been the Federal Government Senate Inquiry into the Commonwealth, State and Territory Disability Agreement, where we made a very, very detailed submission, making very strong recommendations about what needs to happen to improve supported accommodation services and we highly recommend that submission to this committee. We also made a very detailed submission to the current Commonwealth Inquiry into better support for carers and that is very germane again to what we are talking about today.

We have made detailed submissions over and over and over again about the need to either do one of two things: provide sufficient out of home accommodation support services to enable families to relinquish that responsibility or provide the support to families that they so richly deserve to allow them to have a decent quality of life and to give them the support they need to carry out this duty. Clearly, since we provide 93 per cent of all the cared accommodation in this state, we’re irreplaceable and you can’t really do without us. As a government you would need to find about $8 billion if you intend to replace carers in the work that they do for people with disabilities in this state.

One of the critical issues that we want to raise with you is the lack of government will to introduce population-based benchmarking that will allow for the adequate funding of disability services in this state. Clearly, to again talk about population benchmarking, we do that and we do that very, very openly and very, very plainly through the Senate Inquiry and we have actually set out a complete analysis of what needs to be done in order to make that happen. We know that population benchmarking has been in aged care now for decades. We know that in aged care 22.5 per cent of the people are expected to have a severe or profound disability. In the under 65 age group, which are the people we’re talking about today, we know that 3.9 per cent of the total population under 65 have a severe or profound disability.

It’s very simple then to do the simple maths which brings an equal equation for both groups. So a half of 22.5 per cent is 11 per cent approximately or 110 places per 1000 of the population in aged care, which is what aged care is delivering. They are at the moment delivering 108 places per 1000 of the aged care population. To do the same in disability you need to halve the 3.9 per cent, 1.8 percent, which gives you 18 places per 1000 of the population under 65. People, in order for you to do that, the Victorian Government will need to increase its funding by – to three times. So the current $1.1 billion that is spent on disability services needs to be increased to about $3.4 billion if that benchmark is to ever be reached.

This being the case we clearly know why there is a crisis in disability accommodation services in the state and throughout the nation. We know, for example, that there are more people on high need accommodation waiting lists in Victoria than there are people who actually receive an accommodation support service. So, for example,
there are only 5020-odd people receiving a bricks and mortar accommodation service through Victorian Government funding. There are just as many, 5000 people on high need and priority need accommodation waiting lists for accommodation or accommodation support. Again, we also talk about the ridiculous – ridiculous and non-sensical policy position that the Department of Human Services has taken in this state, where their policy says to people with disabilities, we’re not allowed to have institutions in this state, we will only offer you accommodation in a five or six-bed house or individual support in your own flat or your own unit.

At the same time, however, they turn a blind eye to the fact that more than 2000 people with a disability, with acquired brain injury and with mental illness and chronic illness are eking out an existence in for-profit supported residential services in this state in 20, 30, 40 and 100-bed facilities which are, of course, according to the Department, not counted, so not institutions and it doesn’t matter. Again, we say that the Victorian Government needs to radically reform the way that it provides disability services. It needs to make sure that people with disabilities under 65 years old have the same choices in accommodation options as are the choices that are currently offered to people who are over 65.

It is gross discrimination to say to one group of disabled people, no choice for you, but to say to the elderly people, any choice you like: nursing home, hostel, village living, cluster apartments, a whole bunch of aged-care units, village living, anything at all you want you can have if you’re an elderly citizen, but you cannot have it if you are a person with a disability. So, for example, I am currently, and have been for life, the primary carer for my 39 year old deaf, blind and profoundly disabled daughter, who is totally dependent because of rubella syndrome. She is incontinent, she is diabetic, she requires 24-hour care 365 days a year. She has been on an accommodation waiting list for far longer than I can remember.

When the government in their wisdom decided to change the recording system to a service needs register and they sent out a whole bunch of new forms, I discovered that they had very conveniently taken my daughter off the service needs register, because they’ve changed it so that only people who need a service now are people who will be recorded. So that brings us to the next issue of the way the Department records those people who need an accommodation and support service, and in order for them to make future plans for all of those people who will need accommodation support in the future, that system does not exist. So we’re only going to record those who are a high priority for an accommodation service now on the needs register, otherwise you don’t need to worry, come back and apply to me when you say you need it.

Well, come on, people, my daughter has been needing this accommodation service for years. I have been waiting for her to have an accommodation service for years. All of the carers who are in the 60s, 70s, 80s and even 90s have an absolute right to expect that the support they have provided to their disabled sons and daughters all their lives will have the government say, well done, good and faithful servant, now we’re going to take that responsibility away from you and we’re going to provide people with disabilities with their own home to live in. Be aware of this when the Department says people with disabilities have the right to live in the community.
What they really mean is, keep them in the family home in the community for as long as you possibly can keep them there because that saves us a bucket-load of money.

It doesn’t matter how much the family is suffering. It doesn’t matter how much the person with a disability would prefer to live somewhere else, they have no more choice over what is happening today than we have a choice over what is happening today. My daughter is currently being provided with a service in an aged-care facility – yes, she is, because my family home is for me as an aged-care citizen, so therefore my daughter is currently living in an aged-care facility, okay, and that is what governments conveniently want to overlook. It’s not right, it’s not just, it’s discrimination and we need you to understand that so that you will make very strong recommendations that that whole system be completely reformed and that people with disabilities are given the same right to access their own accommodation choices within the system that is provided in their state.

One of the other critical issues that we have to raise is about families having a say in what is happening to them and the people they care for. So we’re talking there about the Victorian government needing to fund disability family advocacy services. We ask for that again and again and again for this very simple reason: at 93 per cent of all cared accommodation being provided by families, we have a right to expect the government will support us to ensure that we have a place at the policy and planning table, that we are on an equal footing with funded disability self advocacy, and that we are on an equal footing with funded service providers, each of which have government funding at the federal and state level to provide them with advocacy services and peak bodies. Families have no such privilege.

Families have a right to expect that government will provide them with the same level of advocacy funded organisations at the regional, state and federal level that will allow them to have their rightful place with the other pretenders to the throne – that is, service providers who only deliver less than 10 per cent of all services, and disability self advocates, and their advocacy organisations that speak for them but do not speak for the severely and profoundly disabled people we care for who cannot speak for themselves. So we want you to recommend that the Victorian government will, as a matter of priority, fund disability family advocacy networks across this state, commencing at the regional level and progressing to having our own peak organisation in the state that we ourselves are able to own and to manage.

The next issue that we want to raise is about the amount of support that families themselves receive. So we’re talking about having to go with begging bowls to the table of the government to ask for in-home support, out-of-home support, respite support, any other kind of support that you can think of. Families are constantly being told by government agencies and by service providers that if you’ve got a service from one agency you can’t have a service from another agency because my goodness me, that’ll be double dipping. Double dipping, do you mind, okay? We have a constant argument with the Commonwealth Government that the states actually fund foster carers to the tune of four to $800 a fortnight, means test free and tax exempt.
Means test free and tax exempt payments to foster carers. But family carers, what do they get? They get nothing. They get a $50 a week carer allowance, is what they get, okay? Let’s not talk about the carer payment, because that only goes to 116,000 people and it’s an income supplement. It has nothing to do with payment for caring. So your family carers are getting really angry and really, really frustrated that, having been unable to continue to cope with their profoundly disabled child because of the lack of support, and they say at the end, “I’m going to give this child up to foster care because I can’t possibly care for it any longer. Here it is.” The foster carer immediately gets $800 a fortnight, 50 hours of paid childcare a week, a weekend a month off, and all the respite that they possibly want to have. How wrong is that?

We need you to be recommending that there be a review of the way foster carers are supported and the way family carers are supported so that there is equality and justice in the system. The next issue that I want to raise really quickly is the reason that none of these things are available to us is because we have no legislated entitlements, no legislated recognition, and no legislated rights. We remember back to the progress of the disability bill, and we say to this committee how angry carers in this region and this state were that the disability bill was marched through Parliament, ignoring all of the recommendations that were being made, that carers of people with disabilities be recognised in the disability bill, for the very simple fact that we provide 93 per cent of all their supported accommodation needs, and then we’re ignored.

We were completely ignored. So again, we were basically told by the government of Victoria, you don’t care – “We don’t care, and you don’t matter.” That is so wrong, and if you want to keep caring into the future, you really need to be taking on board the issues that we raise, and you need to be taking on board all the issues we’ve raised in our submission, very detailed issues, and we need you to be saying, “We value the family carers who provide so much support to people with disabilities in this state, and they deserve to have a better deal.” Thank you.

MS POWELL: And can the people down the end hear that? Yes? Firstly, Jean, thank you very much. What you are saying are things that people have been saying to me as a member of Parliament and to other members of Parliament over a number of years. I guess the reason this committee is travelling around the state is because of those issues. We’re realising that we’re hearing, particularly from this area, that there is a crisis. We’re also hearing that there’s not one-size-fits-all. So what we’re hoping to get while we’re here, the issues, what we’re hoping to get is some of the answers about what sort of accommodation, given that I know a lot of people prefer to look after their children, if you like – your 39 year old daughter, and some 50 year old children with a mental disability – in their own home with help and with respite.

There are others that want to put them somewhere where they know they’re being looked after in safety. So what we’re also looking for is while we’re listening to the stories, we also want to know what you as the experts of caring for people with a disability believe is the best way to accommodate some of these – some people with a disability, because you are the ones that know that not one-size-fits-all. So as well as hearing the issues, we’d like to really hear about what you think the options are. And we’ve been told that there should be offered a range of options, from in-house to out-of-home care, to respite, and we need to know as a committee what some of those issues are, and I know in your submission you touched on those.
So my question to you is, has your group thought about issues like – and I know there was the issue of institutes, and people don’t like that word. But is there a place in today’s society for special places that will house maybe 20 or 30 people with a disability in a better-managed way with people there on staff all the time, because sometimes that one-on-one costs so much money that we need to look at some people who can’t live in the community but do need to have that support and that safety of living in – whether it’s a private clinic or whatever they call it.

MS TOPS: Yes, absolutely. And we agree with you entirely on that. And that’s why we raise the issue of the 2000 people that are currently living in supported residential services of up to 100 beds, okay? They’re living there in a less-than-satisfactory environment. If they had the same level of support and care that people in a group home had, for example, then I’m sure that those people would be relatively content with their lives, but that doesn’t happen. So we’re saying that families and people with disabilities, and our knowledge of them, is that they need access to the same range of services that everybody else has. So there are large numbers of people with disabilities who would perfectly happily live in hostel-type accommodation.

All they really need is somebody who’s there to say, “Johnny, it’s time to get up and have your shower. Your work program starts in half an hour and you haven’t even had breakfast yet.” They need somebody to say, “You need to go to the bank and get your money because you spent it all,” and so they just need small levels of monitoring, and you are providing them with a cost-effective and quality service if it is funded properly. And again, we say over and over again to people, “What’s the institution?” A bank is an institution. A hospital is an institution. Nursing homes are never referred to as institutions; they’re always referred to as aged care residential services. And there’s only one reason why that happens.

It’s because people still hark back to the days of the bad old institution, and in reality what was wrong was not the size of the roof, and it wasn’t the number of people, it was the pathetically inadequate support that those people received. It was the lack of external monitoring. It was the lack of accreditation. It was the lack of somebody outside of the Department providing an overview of what was actually happening to these people, and it was the lack of a sanctioning system that says to agencies providing services, “If you don’t come up to the mark, if you don’t meet the accreditation criteria, out the door you go.” So it’s not about the size of the roof, and economies of scale mean you have to think about different options in order to meet the needs of these people.

The other issue that we believe is preventing the growth in proper accommodation services in this state is that the Department of Human Services themselves should get out of direct service provision. The Department of Human Services at the moment is the funder, it’s the provider of policy, it’s the person who decides who will be funded, and at the same time it delivers the sanctions it also is the person who runs the service. It is grossly inappropriate for government to be a direct service provider in disability services. It happens nowhere else. The Federal Government is not a direct service provider in aged care. The government is not a direct provider of service in any other human service endeavour.
You’ve got to find a way to get the government out of direct service provision so that your service providers, whether they be not-for-profit or for-profit, are governed by accreditation systems, monitoring systems, evaluation systems, and sanctions when they don’t comply.

THE CHAIR: Yes. You’re next.

MR SHAFFER: Thank you, Jean, for your once again compelling account on behalf of Gippsland Carers. I appreciate the things that you’ve said, and I’ve taken notes, and we certainly are committed to making sure that the observations that you’ve made will find their way into the final report absolutely. But I want to ask you for a moment if you could share with us the view of Gippsland Carers in relation to the broad scope of what successive governments have tried to do, with shortcomings I accept, and in particular of course over the last decade, say, where the Disability Act is now in place, and I appreciate the remarks that you made about the place of carers not being expressed in that bill, and we debated that and argued about that at the time.

I also ask you to perhaps reflect on the state disability plan, and on the policy position of individualised programs and plans, and the resourcing that has been put into the area of disability, and the A Fairer Victoria policy, for example, and whether Gippsland Carers has a view about whether generally the concept is right, generally the way that it’s facing is correct. I don’t want to put words in your mouth, and I’m sure I can’t even if I tried, but just reflect whether you think that there are things that we could say to government in our report that is has got right, given the range of perspectives that you’ve just shared with us.

MS TOPS: Okay. In terms of disability services, governments over the years haven’t really got a great deal right, okay? And that’s clearly evident in the fact that we know that if benchmark funding were applied you’d be short of funding by three times what you currently provide, so therefore what government provides is the minimalist position. However, having said that, some of the work that’s been happening over taking the control of what happens to you in relation to being in a service, away from service providers who say, “Well, there’s this and this and this and this, and if you’re a round peg and you can’t fit in a square hole, well tough, off you go somewhere else.”

So individualised funding is probably one of the most positive aspects of what’s happening today, but I want to emphasise as well that in doing individualised funding with the current system, there’s a very real danger that the people who will be slotted into the individual funding system will be the easy peases, okay – the people with a mild to moderate, the walking, talking disabled, if you like, people who can speak for themselves – and that the hard baskets, the people with severe and profound disabilities that we take care of at home, will be the last ones to be offered or to participate in individualised funding.

And then again, the issue over whether or not individualised funding can be managed by a totally over-fraught and overwhelmed family who are at the end of their tether in providing a care service can, in fact, be managed; I believe it would only be managed, for most people in that circumstance, through a brokerage arrangement, and not through putting the money in the disabled persons bank, and saying, “Here you
are, mum and dad. You go off and organise the service, you hire the staff, you worry about the person who doesn’t turn up on the day, that’s not our responsibility. You’ve got individual funding.” It could be seen as being a cop-out.

And, so, we sound a warning bell that whilst we agree with the principle, unless the practice is put in place, that makes sure that people are given packages that actually reflect the need that they have for support, that the whole thing is a way of saying, “We’re going to opt out of this funding process altogether, really, and it’s over to you, family, you can do all the work, including keeping your microphone working.” Okay, so, you know, the idea that people with disabilities are to be integrated into the community is really a nonsense, isn’t it, because since 93 per cent of all the people with a severe or profound disability are in our family homes, and we’re in the community, what does “in the community” really mean?

There’s a whole bunch of rhetoric, isn’t there? And the 10 year plan talks about it. It talks about community inclusion, and people with disabilities having choices and rights, but the bottom line is that unless you provide the resources for those rights to be upheld, nothing changes.

MR NOONAN: Thanks Jean, thanks Bill. I just want to go to your submission, if I could, and ask a question – perhaps a clarification, rather than something else, and the page that I’m looking at is in your executive summary, page 3.

MS TOPS: Yes.

MR NOONAN: And what you’ve basically done is you’ve responded with some recommendations to, I suppose, each part of the reference that the Parliament has been given, and you say very strongly that the Victorian Government, in the first line, ought to opt out of direct service provision altogether. I suppose where I ran the highlighter through the submission was the next recommendation, where you say that the Victorian Government provide age appropriate nursing level of care facilities, and age appropriate supported accommodation services for all persons with dependent disabilities aged of 30 years as a matter of first order priority. I just wonder whether you can clarify that, because it could appear a contradiction in terms.

MS TOPS: Okay, well, sure. The Victorian Government is not the Department of Human Services. That’s the first thing. Okay? So, you appoint the Department of Human Services to deliver Government policy, and you give them a bucket of money with which to do that. Okay? So we’re talking about the Department removing itself from direct service provision. Okay? Because they manage accommodation services, they manage respite services all over the state. They should opt out of those direct service provision choices, and that should all be given to the non-Government sector to manage, so that the Department can concentrate on monitoring, evaluating, policy making, making sure the funding is available to meet everyone’s needs, establishing waiting list, doing forward plans. Okay?

So then, when we say that the Government needs to provide the accommodation services that people need, we’re actually saying embrace population based benchmark funding, and we’re actually saying the Government needs to up the ante on the amount of money that it provides. You cannot make a silk purse out of a sow’s ear.
You cannot give people the accommodation choices they have a right to have unless you have the funding to do it. Why the people over 30? That’s because 93 per cent of all of the people with a severe and profound dependant disability, and please understand we make that distinction, there are people with a severe and profound disability living independently and doing very nicely, thank you.

We’re talking about the 30,000 or so people with a severe or profound disability who are currently living with ageing parent carers in their state. 30,600, according to the ABS/SDAC survey. All of those families who have cared for those people for 30 years and more have the right to say, “We don’t want to do this any more,” and they have the right to say, “We think it is in the best interest of our son or daughter that they live in their own accommodation.” Does that answer the question?

MR NOONAN: I need to – I’ll just - - -

MS TOPS: Yes.

MR NOONAN: So, without rewording your submission, I think what you’re essentially saying to that second recommendation is that the Victorian Government provide funding for, rather than the accommodation, through DHS.

MS TOPS: Yes.

MR NOONAN: Okay. I just wanted clarification. Thank you.

MS TOPS: That’s what happens when you write things in a hurry.

MR NOONAN: That’s okay Jean. That’s the value of this.

THE CHAIR: Jean, just quickly, could you please clarify if you want the Government to fund the Disability Family Advocacy Organisation?

MS TOPS: Yes.

THE CHAIR: Can you just elaborate on that?

MS TOPS: Yes.

THE CHAIR: What sort of shape and what – the role they would play?

MS TOPS: Thank you. Maybe I can clarify that a little bit by just reading you a little bit from the notes I made and hadn’t used, and this gives you a bit of an idea of the dilemma that we’re in. We said to the Better Support for Carers Inquiry that there was a very real need for disability family advocacy to be funded, and we said it for this reason; the Australian Federation of Disability Organisations made a submission to the Better Support for Carers Inquiry, and they said this, and I quote:

AFDO would like to see carers acknowledged for their contribution to society, but that acknowledgement should also include an understanding that the work of carers should actually be the work of paid professionals.
So, what we had here is an untenable, unacceptable, anti-family culture, that we know is out there in spades in disability self-advocacy, and in service provider organisations. In spite of the fact that we do 93 per cent of all of the support, service providers treat us as non-professionals, unpaid, volunteers, whatever you like to call us. We’re saying it’s time to put a stop to that. It’s time that families had their own support organisations, and we want families to have a disability family advocacy network that is currently being proposed by the National Carers Coalition, and that is that there be, the same a disability advocacy, a regionally based carers advocacy organisation in every one of the regions in Victoria and throughout the country, and that those organisations would then propose the establishment of their own Victorian peak body that would then be able to speak on State level on behalf of the issues raised by the regions, and the reason why we need them to be in the regions is because carers are predominantly prisoners in their own homes because of their caring responsibility.

They need locally based support organisations very much similar to Gippsland Carers Association that is totally unfunded, is entirely voluntary, and provides a really, you beaut, wonderful service to the carers of Gippsland, and we do it for nothing, and we’re saying it’s time to put a stop to that. It’s time that we had our own funded organisations. Base them on the same principle that you fund disability advocacy, regional, state, and federal peaks eventually, but starting from the grass roots, so that they’re owned by carers, so that carers can believe that these organisations will provide them with the support and the voice that they need to have, and that those organisations will have the reputation of being able to take their place at the policy and planning table alongside disability advocacy, and alongside service provider peaks, because we deserve it. We provide 93 per cent of the service.

THE CHAIR: Thank you Jean. I am conscious of the time. Before we start the lecture, we’ve got, I think, two more witnesses. Therefore I would like to call the next witness.

MS TOPS: Okay, Bill - - -

THE CHAIR: Then we would like to - - -

MS TOPS: Bill is also with Gippsland Carers, and would like a couple of minutes.

THE CHAIR: Sure.

MR NOONAN: How many witnesses have we got?

THE CHAIR: Then we have – we’ve got two more. Yes, go for it.

MR SKINNER: Thank you very much. When you’re as chronologically enhanced as I am, this could be the last chance I have to speak about the unmet needs of the disabled and family carers. Our precarious situation – or my precarious situation is my wife is currently in extreme poor health, due to the fact the she’s been caring for our daughter for 48 years, and during that time, for 40 of those years, there was no respite at all. Our daughter was having 15 to 20 seizures, so it will give you a bit of
an idea how my wife had to put up – what she had to put with, and I was lucky, I went to work. Over the past 15 years or so, I’ve lost count of the numbers of forums, inquiries, seminars, conferences, community consultations, etcetera, in relation to the disabled and family carers. Really, the unmet needs of family carers have been known since the Australian Bureau of Statistics in 1993 came up with a – all the issues that highlighted the critical needs and issues of family carers and the disabled.

In February 2005, a state minister – Victorian State Minister – after three afternoon interviews and talkbacks on the radio – ABC 774 – came up at the end of those three days, with five statements. This is in 2005. The first one was, “Dollars are not a problem.” The second one was, “Options are many.” The third one was, “Government and opposition are as one.” The fourth one was, “The community needs to declare their requirements and we will take positive action.” And the fifth one, “The carers and the disabled will choose, not the Government.” Now, you may ask, if this was the case in 2005 – we’re now in 2008 with another inquiry – why wasn’t this acted upon? We have a situation called – the Government brought up about mutual obligation. You know, you give, we give. It’s a Government buzz word, and everybody, politicians, and so forth, bureaucrats, use it. In September 2000, the Federal Minister granted private schools, all their students, up to 5721, and the reason for this – and that’s quite right – the reason for this was because the private schools saved the Australian Economy $2.2 billion per annum. The very same year, 2000, the Australian Institute of Health and Welfare came out with figures that said family carers save the Australian Economy $23 billion per annum. And how much were they granted? How much were we granted? Nothing. Is that fair and just? I don’t think so.

I wonder what would happen – Jean mentioned the fact the 93 per cent of carers are, you know – look after people – the disabled. I wonder what would happen to the system, if say, 5 per cent of family carers quit their role, and let’s bear in mind that about 20-odd per cent of family carers are aged much more than 65 years of age. There was another so-called inquiry – sorry, major inquiry. It was the senate inquiry into the CSTDA. It was Australia wide, you know, 150-odd submissions were made Australia wide to the inquiry. About 120 people were called up as witnesses. Jean was one, I was another, in Melbourne. This inquiry took two and half to three years to complete, and came up with 29 recommendations. Has anybody read the recommendations?

There’s a couple of bits I will read out, and not the 29 I can guarantee you, but recommendation number 21:

_The Commonwealth State and Territory governments jointly commit as part of the fourth CSTDA to substantial, additional funding to address identified unmet needs, specialist disability services particularly for a combination services and support._

Another part was:

_A partnership between governments, service providers and disability community has set up policy priorities and improve outcomes for people with a disability._
And so it goes on over the series of recommendations. I now believe that maybe this CSTDA Inquiry is now null and void. It seems staggering to me that the governments, and I’m talking about both Federal and I’m talking about State governments, do not know the level of needs after all this time. So now we have another inquiry. We trust that this inquiry results in some positive action for I believe that if you are not part of the solution you must be part of the problem. I also trust that the people – thank you. I also trust that the people from this inquiry do not join the ATNA Club.

The inevitable excuse for poor support or lack of support has invariably been: we don’t have enough dollars. What was the last surplus we had? How many billions of dollars was that? The real reason is that there is no legislated entitlement to disability and family carers and you can’t change what you don’t acknowledge. Thank you.

MS POWELL: Just a very quick comment. We are not a Parliament, we are not a government committee, we are actually an all party committee, so there is government and non-government on, and I will tell you and I will make a commitment to you that we will be listening and that’s why we are travelling around the State to listen to people like yourselves who do care for carers and where you say, what would happen if 5 per cent of carers quit their role, I think that most governments would know that they wouldn’t because they care about the people which is why they probably know that they are not going to be doing it, so that’s not going to be an outcome because we do value what you do as carers.

We have heard it but just again to say, Bill, that it’s a commitment from me and I guess my committee members, that as an all party committee we will be taking on board everything that is said and we will be making some recommendations.

MS ……… : Could I comment to that?

THE CHAIR: Can you please wait until the workshop starts because you will be given an opportunity during the work shop session to raise your views. I think at this stage I will get on to the next person which is Mary Kooloos.