

**THE PARLIAMENTARY STANDING COMMITTEE OF COMMUNITY DEVELOPMENT MET AT THE BURNIE LIBRARY, ON TUESDAY, 29 APRIL 2008**

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**INQUIRY INTO ASSISTIVE TECHNOLOGY AND EQUIPMENT FOR PEOPLE WITH DISABILITIES**

**Ms ANGELA DODD**, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** (Mr Finch) - Welcome, Angela. You know what our inquiry is all about and this is part of our committee, those that are available. Heather Butler is going to join us as soon as she able to, within about 20 minutes. But we are recording on *Hansard*, so your evidence will be there for the other members to read. I intend now to hand over to you and if you make your presentation, make the points you need to make and then we will be ready to get in a queue behind Brett Whiteley to ask you questions.

**Mr WHITELEY** - Might even ask them along the way, so we don't forget them. Kerry does not like us doing that but we will have a go at it!

**Ms DODD** - It is probably best to start with what I deal with. Tara, my daughter, has just turned seven. She has a rare genetic disorder called Aicardi syndrome, of which there are fewer than a thousand cases in the world. We have to deal with that daily, the main problem being uncontrolled seizures. She cannot walk, talk or use her hands. She has agenesis of the corpus callosum, which means the right and left sides of her brain do not communicate and she has problems with her eyes. We were told she would be blind but she is not. But there are some vision issues.

So daily we deal with the medical stuff. There are complications around that. I was in Melbourne last week for work and she ended up in hospital, so I had to make a rush trip home. She has bowel blockages and urinary tract blockages - you name it. So you deal with that daily, those types of things. Then there is the emotional trauma that you go through - wondering whether you are going to wake up in the morning and find that your daughter is not breathing. If she has a seizure you are up and down all night.

However, my situation is probably not quite as complicated as some. There are others who go through worse situations. But I know that what we deal with emotionally on a day-to-day basis is pretty huge. We have come to terms with it but that does not make it any easier. You deal with that side of it. You have all of that going on.

Tara weighs more than 30 kilos now. We have a portable hoist. We have had two tracks put in at one end of her bedroom and one in her bathroom and the portable hoist is what we are supposed to use to get her in and out of the bath and in and out of bed. Initially they are only supplied one sling, but I managed to convince them that you could not use a wet sling to put her into bed. That does not help us in the lounge room, kitchen or in the car or anything like that. They wanted us to use a portable hoist. I do not know if you have seen them. But if you put her in one of those you cannot even push her on the

carpet. It was not suitable, so, as a family, we looked at our other options. We had heard about tracking and we decided that would be the easier option because even though we were told she would never walk, she is fine with weight bearing and can stand for a couple of seconds. She has to be aided, but we think that if she was in a sling, that could be part of her therapy. There are lots of therapies that you have to do, but my back is not strong enough to hold her and get her to walk to places like the bathroom and things like that. We figured this tracking through would be a good idea. We looked into it and were quoted \$9 500 for the tracking without the installation. Installation is about \$5 000. Any submission we put forward for that was rejected. Luckily, the community, in different ways, have raised \$6 000 towards that. So we have the tracking at home. We are just trying to save the money now to get it installed which will be around \$5 000. So if we can get that in, that will aid us around the house.

We bought a Kia Carnival as a vehicle because we could not get her in and out of the Pajero. The Kia Carnival seemed to be a well-suited vehicle. But same again, we cannot get her in and out of it now. We finally got a wheelchair but six weeks after we received it the wheels buckled. It still does not have all the parts for it and that was purchased by the Variety Club because the Government would not supply the funds for it.

**Mr WHITELEY** - How long had you been waiting for the wheelchair?

**Ms DODD** - A long time. The days roll into one another.

**Mr BEST** - Sorry to interrupt, but why wouldn't they get you a wheelchair? We heard evidence yesterday that, if people had a bit of support from somewhere else for some reason, the department would not provide support. Is that your situation?

**Ms DODD** - We applied and did not get it. The Variety Club heard about what was going on and they stepped in purchased it. Tara has stroller, one that was purchased privately because once again it was refused. As I said, she is starting the weight bear and so the wheelchair is a better option because we could not get her to stand off the stroller because of the way it leans back. So we needed the wheelchair to try to get her to stand. It does not help. She is sick at the moment. As I said, she was in hospital last week. When she is sick there is no assistance at all from her, so it is all on us to do.

**Mr WHITELEY** - Those must be issues we heard about yesterday also - OH&S for a family having to deal with that.

**Ms DODD** - Greg's back is absolutely bugged. He does not sleep all night. We both have regular back care because of that fact and Steph, her carer, had two vertebrae shot and a spur growing on her neck because of lifting Tara.

**CHAIR** - The girl is only going to get heavier, isn't she?

**Ms DODD** - Yes. Her medication means she gains weight and she holds the weight because she is inactive. So she is actually quite stocky. I call her my little Buddha. But I must say that she is absolutely gorgeous. She has the most beautiful smile; she giggles and her laugh is very infectious. So, do not get me wrong; I sound like I am bagging her out but I am not.

**Mr WHITELEY** - Yes, it is just a medical and physical reality.

**Ms DODD** - We could not get a chair to feed her in at home so Pop made her a chair, which was fantastic. However, her physical abilities have gone backwards in some ways, so we realise that this chair is no good for her any more, much to Pop's disgust. We have actually applied for a feeding chair but there has been no response on that.

**Mr WHITELEY** - What are they worth?

**Ms DODD** - About \$3 000. I have been home with her since Friday until today and I cannot leave the room because she falls over. I have to sit her up in the lounge chair and tip it back and then hope to God she is still sitting there when I get back. I literally cannot leave the room because she falls over or she goes into a seizure. We have asked for a corner chair, a specific chair so that we can sit her on the floor. It has a tray on it and she can watch TV or whatever. I cannot cook tea. It is just such hard work at the moment. That application went to them last month. I asked about it yesterday and it has not been approved. I am not sure when the next meeting is.

We have asked for assistance on the car but there is nothing. I work full-time and I had this conversation with my sister when I was in tears yesterday. I said, 'What am I supposed to do? I'm so exhausted. I'm so damn tired. I work full-time and I have a high pressure job'. That is my choice, I have a career, but I have it to support our family. I am the main income earner. We are on a farm and most people know what farm life is like. Where does the money go? Back into the farm. It really is hard work and every time you turn around you face something else and I just throw my hands in the air.

**Mr WHITELEY** - Just on that point, and take my comments as best I can articulate because I do not want to cause any offence, it is probably always going to be hard work. However, the question I want to ask is what amount of that exhaustion and emotional stress to your family, and you particularly in having a full-time job as well, is brought about by financial pressures? You love your job but you probably need to work because you do not have a choice -

**Ms DODD** - No.

**Mr WHITELEY** - so how much of that pressure comes about from worrying how the hell am I going to pay for this and that? You just named five things in three minutes. If we had to come up with those for our kids we would be screaming from the roof tops, but we get a choice; we do not have to provide it. How much of that pressure is linked to that?

**Ms DODD** - A fair percentage of that pressure. I said to Kylie yesterday that I could just quit work, but then I could not even afford to buy incontinence aids for Tara if I quit work. I really could not. She has just got onto the CAAS scheme and that is \$470 a year. I would actually spend that before June.

**Mr WHITELEY** - So you are spending how much a month now?

**Ms DODD** - I was spending \$2 000 every three months.

**Mr WHITELEY** - Just on that?

**Ms DODD** - On incontinence.

**Mr WHITELEY** - That is \$2 000 every three months - \$8 000 a year and they give you \$470. A fair bit of the stress that you are referring to is linked to that?

**Ms DODD** - Yes. I do not say this in any way, shape or form to offend anyone, but I feel that if I did not work there would be assistance there and that would be easier. I have put in for an ISP for before and after-school care. I pay \$200 a week for before and after-school care.

**Mr WHITELEY** - Just on the ISP, the individual support package, no doubt the department or whoever you are working with have asked you to formulate everything that is involved in that. How much does this challenge with Tara cost your family in any given year?

**Ms DODD** - We worked out that without any normal childhood care -

**Mr WHITELEY** - Which you cannot. Everybody is looking for that.

**Ms DODD** - and when we put the submission in they were talking to me about doctors appointments and all that and I said, 'I'm not going into that because if Tara did not have a disability that would be a cost that I would have.

**Mr WHITELEY** - That any other family would have as a normal part of life.

**Ms DODD** - Yes. When I worked it out it was about \$25 000 a year - based on her disability.

**Mr WHITELEY** - That is just like recurrent expenditure but would not account for the purchase of \$14 000 worth of tracking or a \$3 000 feeding chair? These are the recurrent costs?

**Ms DODD** - Yes. I put in the ISP and after much fighting and argument I managed to get six hours respite on a Saturday. When that person arrives I run to do everything that I have to do, like the groceries, the washing -

**Mr WHITELEY** - So it is not respite.

**Ms DODD** - No. Greg just growls at me because I do not stop, do not sit down, do not do anything. I might go and have lunch with my sister occasionally but the boys need new football shorts - the normal kids stuff.

**CHAIR** - You have other children?

**Ms DODD** - I have three stepsons - 18, 17 and 14.

**Mr WHITELEY** - They don't need any attention, do they, at that age?

*Laughter.*

**Mr WHITELEY** - With the ISP, does that \$25 000 include care?

**Ms DODD** - That includes the cost of child care.

**Mr WHITELEY** - At the moment?

**Ms DODD** - Yes.

**Mr WHITELEY** - What about the actual supported care for the rest of Saturday?

**Ms DODD** - No, that is not included. Once I got the ISP I found out that I do not get the respite any more.

**Mr WHITELEY** - Yes, once you have done that it is all over. You have to build that into your ISP?

**Ms DODD** - Yes.

**Mr WHITELEY** - You will need to go back and redo that because that is the trick.

**Ms PUTT** - So one of the problems is not knowing how everything fits together and where to go for what?

**Ms DODD** - Yes. The people whom I work with do a good job but even they do not understand that I don't know that.

**Ms PUTT** - Yes; they know so they think everybody knows.

**Ms DODD** - I know I am guilty of that at work. It is a communication thing.

**Ms PUTT** - That is actually something TasCOSS pointed out in their report. People have just no idea what is out there. Sometimes they have gone without things for years and then someone says, 'Why haven't you done such and such?', and they go, 'What!'.

**Mr WHITELEY** - One group said that one of the great recommendations that might come out of this committee is a one-stop shop.

**Ms DODD** - I was actually given a booklet, and it is quite thick, with all the information in it.

**CHAIR** - Angela, who do you actually deal with when you discuss these issues about Tara? Is there a particular person, panel or office that you go to? Who do you actually need to front and deal with?

**Ms DODD** - I talk to Bernadette, who is our case worker at Disability Services. She is great but, like I said, she is also flat out as well. At the moment I just throw my hands in the air. I just do not know who to talk to any more.

**CHAIR** - Does Bernadette give you good guidance through the system and help you to find your way through?

**Ms DODD** - To a certain degree. I can say to you that there are some good things and I need to point out the positives, like the education system. I was one of the ones that actually did not want the early education centre in Stewart Street to stop at kindergarten, but that did not work so Tara is at Spreyton Primary and that has been fantastic. It is a lot of work. There were a lot of meetings involved to get it all set up and all that sort of thing but that has worked really well. I am really happy with the education side of things. I cannot say to you that everything is really negative. I have met some fantastic people through our journey but on the other side every time you turn around you have a form to fill in or you have to justify something.

**CHAIR** - The pathway isn't easy to deal with your issues.

**Ms DODD** - No. It is a huge journey and financial pressure. We sat down last night and emptied a big tub of coins so that we could pay Steph for the next fortnight. That is just what it gets to. We are at a stage in life where we should be planning for retirement. The way things are going, we are going to be among those people on the pension because we just do not have the money - and there will be three teenagers as well. Okay, two of them are working but they do not cover their costs. There is no way that they cover their costs at that age.

**Mr WHITELEY** - Don't they?

*Laughter.*

**Mr WHITELEY** - Looking into the areas of equipment and the Community Equipment Scheme and assistive technology, out of that \$25 000 what would fit into this particular -

**Ms DODD** - None of that. That is just the care. No, I think you can put a wheelchair in there. That was priced at \$6 000.

**Mr WHITELEY** - So incontinence aids are not a part of the equipment?

**Ms DODD** - No.

**Mr WHITELEY** - That is under a different scheme and a different set up?

**Ms DODD** - We are getting to the point now of saying, 'What do we do about a vehicle?' Do we go out and purchase a vehicle and get it set up for the wheelchair so we can hoist her in. I do not have the money for that. What do we do? She is the only seven-year-old I know who has her own vehicle. I say that because Steph comes to our home and takes her to school in it. I still have to get to work so I have the family vehicle. It is not really her vehicle but it is the one that we purchased so that -

**Mr WHITELEY** - So she has transport?

**Ms DODD** - Yes.

**Mr WHITELEY** - Did you pay for that?

**Ms DODD** - Yes.

**Mr WHITELEY** - Also the hoist?

**Ms DODD** - We do not have any lifting aids in that car.

**Mr WHITELEY** - Okay.

**Ms DODD** - So that is hard work.

**Ms PUTT** - I was going to ask about forward planning. It sounds like you are always in catch-up about the things that you now discovered you need?

**Ms DODD** - My sister said to me - she used to work in the Education Department as a special needs aide - 'Angela, you need to plan two years ahead'. I looked at her and said, 'How do I know?'. Two years ago Tara had lost so much weight they thought that she had given up. She was so thin I could carry her anywhere. But now, getting her out of bed, I grab hold of her pyjama bottoms and walk out. It is quite a comedy. She gets crabby with me because of it.

**Ms PUTT** - Because it is quite unpredictable, what you need is a quick response when you need something?

**Ms DODD** - Yes and that is just not going to happen, not the way I see it. We were told when Tara was first diagnosed that she would not make her first birthday. So it is hard to plan. I still do not plan her birthday parties. I said, 'It is your birthday but mummy has not planned anything, but I promise I will next year'. I need to get to that stage. I am sure she understands what I am talking about. She understands more than we think. She is quite smart in fact. So I need to do that for her next year. But how can you sit down and plan for 10 years' time? You hear people with teenagers and I think, 'I cannot even go there, so don't even talk to me about it yet'. It is hard work, thinking where do we go. The way I felt yesterday, I could have handed her over. She was sick. She could not tell me what was wrong. I could not work out what was wrong. I could not get a doctor on the phone. I could not get to see anyone. I just did not know what to do. Then I went to stand up and nearly dropped her. It is this continual thing. You feel, when you bring a child into the world, it is your responsibility and you feel a huge failure because you cannot meet all of your child's needs. It is a big thing. I was brought up to be independent and it is a really huge thing for me to ask for help. Among the things that I have done, going to the media was the hardest thing I have ever done in my life. I just opened myself up to that. It was something that I just do not cope with very well at all.

**Mr WHITELEY** - We encourage that because, as much as that was hard for you, it opens the way for others. I know it was tough for you but be encouraged because it did give permission to some other people to say, 'Gee, I thought I was the only one'.

**Ms DODD** - I know of one older lady who has a 17-year-old son and is still lifting him out of the bath.

**Mr WHITELEY** - Imagine that, and she is getting older as he gets older.

**CHAIR** - Angela, we have had some comment that the priority ratings are okay, but you disagree with that?

**Ms DODD** - Yes.

**CHAIR** - Would you give us your reasons?

**Ms DODD** - Priority ratings, I am just refreshing myself on that.

**Mr WHITELEY** - You said family inclusion in what the priority ratings are would be of great assistance.

**CHAIR** - Family inclusion in what the priority ratings are would be of great assistance. This area seems really confusing and inconsistent.

**Ms DODD** - Yes, because something that is really important to us is not always important to someone else. It is not a priority one so it does not get looked at and I am trying to think of what the last thing was that we had and we had to go and buy it ourselves because it did not even match up. I think it might have been the tracking that was not a priority one.

**CHAIR** - Who would you deal with for that, Bernadette?

**Ms DODD** - No, it goes through a physio on OT.

**CHAIR** - At the hospital?

**Ms DODD** - The community centre at Steele Street in Devonport. We discuss any equipment we need with them and they investigate it and it is then submitted.

**CHAIR** - So you need to go down to Devonport and make your submission?

**Ms DODD** - Yes.

**Ms PUTT** - So someone determines whether that is a priority one. Do they do that against a list of things that are potentially priority one?

**Ms DODD** - Yes.

**Ms PUTT** - So it is not tailored to your individual circumstances, there is just a list out there that in general might be priority one across a range of conditions, but it is not matched to Tara?

**Ms DODD** - No.

**CHAIR** - Do you see what those priority one ratings are?

**Ms DODD** - No.

**CHAIR** - You do not know?



**Ms DODD** - If I say it would be great to have something then they say, 'Oh no, that's not a priority one', so that will not even get looked at.

**CHAIR** - But you do not have an understanding of that before you make a submission. It would save you a lot of trouble if you knew what are in priority one ratings. Then you would not have to go through the trouble of preparing your case, getting your costings -

**Ms DODD** - Even thinking about it; you would just take it out of your thought process.

**Ms PUTT** - If you had an ability to influence what was rated as priority one in your particular case, that would also be really useful, wouldn't it?

**Ms DODD** - Yes.

**Ms PUTT** - Because what is going to be priority one for Tara obviously is not going to be priority one for a bunch of other people but it does not mean that it is not priority one for Tara.

**Ms DODD** - With the car we were looking at different ways with the vehicle, whether we went for a ramp or a hoist or a hoist that is put onto the car. One of those was not priority one and so it would not even get looked at. I think that is what it was; I cannot really remember how that works now. It was one of the issues that we looked at and one of the options that were available we could not even look at it, even though we thought it would probably be a better way of doing things for us. When you want to go somewhere, you want to get in the car and go.

**Mrs BUTLER** - Angela, with a lot of these points you are raising you seem to pretty much by yourself, advocating for yourself. Do you have a case worker who helps you prepare submissions et cetera?

**Ms DODD** - Bernadette has with the ISP, but the equipment is all done through the girls at physio and OT because you cannot even put in a submission for any equipment unless it has been agreed to by the physio and OT.

**Mrs BUTLER** - Would it help if there was less demarcation between those two systems?

**Ms DODD** - Yes, a huge help. But we cannot have something unless Sheree or Victoria approve it or recommend it. I have to convince them first and then get them to sign off on it. They do not agree with the tracking, they wanted us to have the push hoist and I felt like saying, 'You come out and you push them from one area to the other'. There is nothing quick about it, that is one of the hardest things that we have had to come to terms with; you cannot just jump in the car and go somewhere because of the time taken in getting Tara in and out, amongst other things.

**Mr WHITELEY** - This one is a really tough question but it links in with your challenge on birthdays. The tracking is a lot of money but surely that is something into the future that is going to be available.

**Ms DODD** - What?

**Mr WHITELEY** - The tracking, so for whatever reason Tara was not using it, it is not as though that is going to be wasted. It is a matter of taking it and some other child in 10, 15 or 20 years' time could use it. Is that a fair comment? It is not as though it is going to be a one-off expense.

**CHAIR** - It can be utilised somebody else.

**Mr WHITELEY** - Yes, it is not going to be wasted in that sense. It is not going to sit on your ceiling if you do not use it.

**Ms DODD** - And the other thing is if Tara stays with us I do not have to worry about getting a new hoist every year.

**Mr WHITELEY** - That is right because the tracking is going to handle it.

**Ms DODD** - The actual hoist bit might have a weight limit on it.

**Mr WHITELEY** - But the actual track will not.

**Ms DODD** - No. The hoist itself is quite heavy. You have to get on a chair and unhook it from the bathroom, which is why I do not do it, and take it down and then carry it into the bedroom and hook it up there and then get carry it back to the bathroom. They are just things that people do not think about. They do not come to your house and say, 'That isn't very convenient'. Let us face it, our lives are hectic and that is life and it is just not me. Everyone is flat out. You want the quickest and easiest way and what is more comfortable for Tara, and she hates being hoisted anyway.

**CHAIR** - You have never had your home assessed or anything like that? People have not come from the CES to have a look at your house? Have you ever requested that?

**Ms DODD** - Victoria and Sheree have been up, the physios. No, I have not. We built our house and halfway through building we found out about Tara's condition and so we reassessed what we were doing. We changed the plan and built a disabled bathroom into it and we put wider doorways in and things like that. It cost us an extra \$50 000 to do what we did. Everything is flat so we can just wheel everything through. There are a lot of benefits because of the fact that we were building. Greg spoke to someone and they said that there was no funding available unless it is for alterations, but we still have to make alterations because we put sliding doors in with the tracking and you have to have opening doors so we have to buy a couple of doors and because Tara is only seven I still want her to have a bath so we have to go and buy a square bath - and that is my choice - and that will go into the disabled bathroom, so there are those types of things.

No, other than the physio on our team, no-one has ever come up. When she came up, Bernadette said, 'I know a lot of people out there who would be absolutely thrilled to have this house'. It is open. We have not got little passageways and stuff like that. We have a lot of benefits based on what we knew when we were building the house.

**Mr WHITELEY** - Tara has a challenge that is faced by only 1 000 people across the world.

**Ms DODD** - Yes, a bit over.

**Mr WHITELEY** - However, there are too many, sadly, other children that are facing different but similar challenges. Not all parents cope with that, do they? You are obviously coping, even though you said you are exhausted.

**Ms DODD** - There is a stage when you don't.

**Mr WHITELEY** - Again, these are some tough questions but I want to ask them. Not all parents choose to continue the journey, as you call it. I think that is admirable, I think it is fantastic and it is the ultimate. When they do not choose to continue as you have, those children go into care. At what sort of cost to the taxpayer is that compared to what you and Greg and your family are paying? Do you have any idea?

**Ms DODD** - No. I would not even consider how much it would be but I have heard it is in the tens of thousands a month.

**Mr WHITELEY** - You can see what I am asking?

**Ms DODD** - Yes.

**Mr WHITELEY** - The choice you are making I think is the best one.

**Ms DODD** - And it is best for Tara.

**Mr WHITELEY** - But not everyone makes that choice.

**Ms DODD** - We were told she would be a vegetable but that has not been the case, through our hard work and some long-term good therapies that we use, and this is the type of stuff they are not talking about. We have chosen to send her to a fantastic masseur and I believe he is the reason I still have her today. We pay for that. I am not asking for any of that. I have taken her to different places to look for answers. She has been to Melbourne. That is all part of being a parent. I pay \$200 a week just for after-school care. If she is sick, as she has been, that goes through the roof. The school holidays costs me about \$500 a week. What is the use of going to work, really, when it costs that much money? But I know, for Tara's welfare, I need not to be with her all day, every day because it is too hard. I cannot cope with every seizure. I just cannot cope.

**CHAIR** - Have you quantified what support you have received?

**Ms DODD** - Have I sat down and thought about what I have received?

**CHAIR** - What you have been assisted with?

**Ms PUTT** - The amount of money?

**CHAIR** - Yes, do you have it in money terms? Have you quantified that?

**Ms DODD** - No, I have not.

**CHAIR** - Are you getting a sense that you are not getting the support that you really should be getting in a partnership situation where you have a problem with Tara, an issue, and you are expecting the system, the Government or the agencies, to be part of finding the solutions and supporting and helping you through the journey and you feel that it is a bit one-sided? I am probably putting thoughts into your brain now. I am wondering whether it would be helpful if we had some understanding of just what support you have received and whether that would amplify your argument that you are really not getting the support that you probably feel that you might like to get.

**Ms DODD** - I have worked hard all my life. I have paid my taxes. I am a law-abiding citizen. I do everything right and I raise my kids to do the right things and, as I said, I do work hard. Yes, I feel that I have been abandoned by the Government. I really feel that. As I said, it takes a lot for me to ask for help and I am in a situation where I need help and I feel like I being ignored. I was told a long time ago, visit the loudest person -

**Mr WHITELEY** - Yes, the squeaky wheel.

**Ms DODD** - That kind of thing and it took me a long time to do that. And I have been noisy.

**Mr WHITELEY** - Only recently, I would have to say. The first six years you were not.

**Mr BEST** - As I understand it, you now put in a new submission or your request or whatever and that then gets appraised. Do you think maybe the system itself ought to be changed, that it is not a cooperative approach?

**Ms DODD** - Why don't they come to my house?

**Mr BEST** - Yes, someone could come and sit down with you.

**Ms DODD** - Come and live my life for a day. I have often said this, and not just regarding me but anybody who lives with a disability, 'Come and spend a day in my house'. I get really blasé about it to some extent and then I find that I am nearly ready to crash and my sisters will say to me, 'For Christ sake, Angela, there are not many people who go through what you go through in a day and you need to stop being so hard on yourself'. So, yes, come and see what my life is like.

**Mr BEST** - Why is that then that, say, an occupational therapist or someone like that -

**Ms DODD** - Because they are still only involved in that small part. They do not have to live with Tara - and this is nothing against them. But you know yourself, in your job, if you do not tunnel it, you take on too much. So they can only look at certain parts and that is in defence of them because it is a pretty emotional job for them to watch what we go through and they do come to the home but the majority of the time we go in there.

**Mr BEST** - So really, you would flag some change in the way the application process operates so that there is a more cooperative approach and more of a one-on-one assessment approach to working it through?

**Ms DODD** - Yes. The other thing that really gets to me is: is it because I work and I have a good income that I am ignored? I work hard just so that we can make ends meet. Is that

what is wrong? Do I need to quit work and then, if I am on a pension and I am more of a burden to the Government, is that going to make a difference to all these things? That is how I feel sometimes because I do not know what to do. I am working my guts out. Do I keep my taxes back and pay for this stuff?

**Mr WHITELEY** - The stark reality is, as we heard yesterday, that the scheme only has a pittance of what it requires. Therefore, sadly, the people who are dealing with it have to have a filter system - these are my words, not theirs - so at the end of the day I would suggest, and you do not have to, that if you sat on that panel and had to choose between you - who works, and good on you and so you ought to and you should have your own life - and someone who does not and you have to decide the last \$500, I will leave it to you to work out which way I think the decision would go. In the absence of the money that is required, those harsh realities do set in, so I think Brenton's point is right.

**Ms DODD** - I know people who are not working. I know one mother who has two children with a disability. She is up all night with one little boy because he stops breathing. She has a monitor and he screams all night long. She has another child as well and is doing it on her own.

**CHAIR** - Angela, would you like to make a final comment? If, from our conversation today and questions, there are things you feel you have not been able to express to us either in person or through your submission, then feel free to submit more material to us. Is there a final comment you would like to make?

**Ms DODD** - I just need to see a change or I will go stark raving mad. I need a better process so that I do not have to fill in so much paperwork, and so that people listen to you. I would invite anyone to come to my home and see what we are dealing with.

**Mr WHITELEY** - We might just do that.

**Ms DODD** - Come and meet Tara, she is an amazing kid. She really gives you a different outlook on life.

**CHAIR** - Angela, thank you very much.

**THE WITNESS WITHDREW.**

**Ms GRACE BROWN**, ACTING PRINCIPAL, AND **Ms FELICITY LOVATT**, SPEECH PATHOLOGIST, BURNIE AND DEVONPORT SPECIAL SCHOOLS, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

**CHAIR** - Welcome, and thank you very much for attending today.

**Mr LOVATT** - Thank you for the opportunity. I am a speech pathologist with the Department of Education. My role is to support students with disabilities in special schools and in regular education settings. My submission today relates specifically to the provision of electronic communication devices for students who do not have functional use of speech. We generally refer to those students as having complex communication needs, where speech might be a feature of their communication but it is not their sole form of communication.

The submission I have already provided for you gives an outline and introduction to those areas but I have prepared a little extra information today around the principles of what we would see as an effective scheme for providing electronic communication devices.

I guess I have seen a great incompatibility with the current Community Equipment Scheme and the way electronic communication devices fit into that. I have worked in the field for about 10 years and I have not had any success, not one single occasion, where I have had a successful submission for a voice-out communication device being granted a client by the community equipment scheme.

**CHAIR** - How many times have you felt that was necessary?

**Ms LOVATT** - To make a submission to the scheme? There would probably be 25 occasions, I suppose, and more when I was working in a different role. In the Education department I am probably not making as frequent applications as I have in other roles.

**CHAIR** - So 25 with no success?

**Ms LOVATT** - That is right, with no success.

**Ms BROWN** - I am the acting principal at both special schools, the one at Devonport and the one at Burnie, and I come from 25 years of working with students with special needs in a variety of different roles. I have just come from a role as physical impairment coordinator and also working in early childhood intervention. I am just supporting Felicity in her request. When we want a device and we have had the recommendation from a speech and language pathologist, for somebody like myself who knows that they are not going to get it, but that is what the child needs, then we have had to go out into the general community and raise the money. That is the only way we have been able to manage it.

**CHAIR** - What sort of cost do these come at?

**Ms BROWN** - More than \$20 000.

**Ms LOVATT** - There is quite a range and that would be the upper limit. Most of them would be between \$4 500 to \$14 000. We certainly have some good statewide assessment processes for the use of electronic communication devices. In the south that is through the Communication Access Centre and up here it is through the Independent Living Centre. The assessment is there; they can provide short-term trials of devices for students but once an appropriate device is identified the options are so minimal. Generally what we do is go through the motions of applying to the Community Equipment Scheme to get knocked back due to lack of funds.

**Mr WHITELEY** - It verges on cruel, doesn't it?

**Ms LOVATT** - That is right. It is an ethical dilemma for us at times because do we provide access for this student to this device for a couple of months and let them realise the opportunities that exist for them and then take it away and say, 'You can't have that because that is an assessment device'.

**Mr WHITELEY** - The pressure that must put on families that cannot afford to buy it must be extraordinary.

**Ms LOVATT** - That is right. It is really an ethical dilemma in many ways. There are families who have the resources and advocacy to pursue funding through a variety club or service club or fund-raising for themselves but there are so many who do not have those resources or capacity and therefore their loved one is discriminated against.

**CHAIR** - I am just wondering about the success you have in getting the response from the community. You would go out to service clubs or a variety club or wherever you go and say, 'We have a child here who needs this support'. Do you find the success rate is high in respect of getting an understanding of your issues?

**Ms BROWN** - What usually happens is, for example, that I have a range of different people from my own community where I live and I know which people to approach.

**Mr WHITELEY** - Which buttons to push.

**Ms BROWN** - Yes, but if people like Felicity and I did not have the commitment to go out there and do it in our own free time and attend meetings such as Inner Wheel, for example, and explain about the family, the child and their needs, then we would not get the response. The money flows in tiny buckets and you have to keep adding over maybe 18 months.

**Ms LOVATT** - And the disadvantage of that approach is that the equipment then belongs to the individual. While technology is changing so frequently it is very difficult for us, as therapists, to prescribe a device that is then going to belong to the individual and has to meet their needs for the next 30 years. That is impossible for us predict. So the situation can often emerge where it meets their needs for a number of years and then their needs change or the equipment becomes redundant or is not maintained because there is no scheme that supports maintenance and repair. By then they are collecting dust in a cupboard and all of that resource and time and effort from the community for fundraising is wasted. It just does not work. Whereas if it was a pooled scheme where the scheme purchased the devices and loaned them on a long-term basis to individuals, when that no

longer met that individual's needs it could be returned to the scheme and be reapplied to a different person.

**Mr WHITELEY** - If it is still current, that is right.

**Ms LOVATT** - There can be maintenance costs addressed through the scheme as well. So it does not work for a number of reasons. What I have provided on your handout is just some principles of what does work best. The best-practice model that is currently operating in Australia is generally agreed to be the Victorian model. I guess we can be seen to be about 17 years behind Victoria in that they went through this process in 1991. They had a system where communication devices were lumped in with all the other equipment needs for people with disabilities. However, it is very difficult for communication devices to be on an equal footing with something like a wheelchair or a hoist because if you are, for instance, trying to discharge people from hospital beds or look after the occupational health and safety of carers, how can a communication device compete with those very physical outcomes that come from mobility equipment. That is always going to be prioritised higher.

**Mr WHITELEY** - In a limited pool that will always be the case.

**Ms LOVATT** - That is why we can never compete against those things. I think there is probably a perception too that there are others ways in which communication needs can be met. We could get some low technology, picture-based communication systems in place for this person - whereas there is no option for a wheelchair. It is a wheelchair or nothing.

So I think there is a lot of incompatibility in having all of the equipment addressed in one single scheme. Victoria has moved to an exclusive scheme for communication devices. It is a statewide scheme for electronic communication devices and they have recurrent annual funding of \$1.4 million. They administer 420 applications per year. Each application has a ceiling of \$7 000 for adults and \$4 500 for pre-school students. The manager of that scheme informed me that the ceiling covers 90 per cent of their applications and for 10 per cent they have to go out and seek additional funding.

**Mr WHITELEY** - A bit of gap-funding.

**Ms LOVATT** - Yes.

**Mr BEST** - How did they go about implementing and deciding upon this policy Victoria, because they would have been the same position as here in that there would be no real support?

**Ms LOVATT** - I know that in 1991 they ran a one-year pilot for having an exclusive communication device system, separate from the mobility equipment.

**Mr BEST** - That would have helped to get it up to a position where you can manage it on an annual basis?

**Ms LOVATT** - Yes. I think they have gathered funding support as time has progressed.



**Mr BEST** - So it would be hard to do all at once?

**Ms LOVATT** - Yes. Importantly, they have allocated some of that funding for the repair and maintenance of devices, some to have a dedicated manager or coordinator of the scheme and some for purchasing the devices. I guess they have built it up over time.

The aids and equipment program in Victoria is currently under review by KPMG. I think that will be completed at some stage during this year, so there might be some more information available later in the year.

**CHAIR** - What sort of assessment is that, do you know? Just how the operation is running?

**Mr LOVATT** - I am not really up to speed with their daily rating.

**CHAIR** - That is okay.

**Mr LOVATT** - Incidentally, I have just put a contact there for the manager of the Victorian scheme if you want to follow that up.

**CHAIR** - I am just making an observation as much as anything, but it seems to me that if this scheme in Victoria is covering 90 per cent of the client applications, then it would be a much easier process for you, Grace, having to go into the community and seek help to say, 'We're looking for -

**Mr LOVATT** - But not 90 per cent of the applications; they cover 100 per cent of their applications. They are able to give 90 per cent of the funds.

**Mr WHITELEY** - In 90 per cent of the cases funds are totally met?

**Mr LOVATT** - The funds are totally met.

**Mr WHITELEY** - There is only 10 per cent that needs a bit of help?

**Mr LOVATT** - Yes.

**Mr WHITELEY** - In other words, it goes over the 7 000.

**Mr LOVATT** - Yes. They meet all of their applications to their scheme for a communication device and there is no waiting list.

**Mr WHITELEY** - So it is your understanding that the need - we have heard a lot about the unmet need and the unknown need - in this area is known in Victoria - I want to ask a question about that in a minute - and met?

**Mr LOVATT** - Yes.

**Mr WHITELEY** - On a population formula comparison, we are probably not talking about a massive amount of money to meet the need in Tasmania, are we?

**Mr LOVATT** - Obviously that is beyond my area of expertise but there would be initial set-up costs to get a pool of -

**Mr WHITELEY** - Do you have the data of what the need is?

**Mr LOVATT** - No.

**Ms BROWN** - There are three regions.

**Mr LOVATT** - We have not kept data on any of that. I would suggest that the Independent Living Centre and the Communication Access Clinic in the south would be able to give you the number of assessments that are being conducted and from there you could determine -

**Ms BROWN** - And also the Independent Living Centre in Launceston.

**Ms PUTT** - Regarding the business about no waiting list, do you know whether that is because the funds that are allocated annually are sufficient or whether they have some flexible thing that expands to fill the need available?

**Mr LOVATT** - I think it is a combination. I think they have great funding but also they have operated this scheme since 1991 so they have developed quite a substantial pool of equipment and they can resubmit that to other individuals once it no longer meets their needs. Remember I said that if it is a shared scheme -

**Ms PUTT** - Yes.

**Mr LOVATT** - ownership does not belong to the client, it is a loan scheme, and it returns when it no longer meets the client's need and can be reallocated.

**Ms PUTT** - There is a whole lot of efficiencies that way.

**Mr LOVATT** - Yes. The managers still felt it was important that some of their funding was still apportioned to purchasing new devices because of the gains in technology and the fact that many devices become redundant very quickly. I think one of the cases Grace mentioned - she did so much work for fundraising - was two or three years ago. I think we are at the point now where that little girl's device is becoming obsolete and redundant and there are much better devices that are now on the market. If there were a pooled scheme, we would probably recall that device and give her something -

**Mr WHITELEY** - Could the recalled device be used or is it completely obsolete?

**Mr LOVATT** - Yes, it could.

**Mr WHITELEY** - It would be okay for someone?

**Mr LOVATT** - It could go to someone who is at an earlier phase in their learning.

**Mr WHITELEY** - Good. I just did not know whether it was completely obsolete or just for her.

**Mr LOVATT** - Just for her.

**Mr WHITELEY** - That is a very good point, so it is not wasted.

**Ms BROWN** - The thing is, as an educationalist, you see the student progressing through a regular school setting. She has average intellect and is unable to speak, and it is the frustration of that, plus she is from a loving family who do not have the financial resources to buy her another device.

**Mr LOVATT** - And because you have exhausted the community capacity to buy it once, it is hard to go back in a couple of years and do it all over again for the same child.

**Mrs BUTLER** - Grace, you were alluding to your fundraising activities. I am wondering how these fit with the Education department. Do they see that as part of your role? Can you tell us about how much time you would devote to that?

**Ms BROWN** - I guess you get known within the local community and now it would be that people may ring me up and say, 'I have raised this much money and I think you are running a particular program in your school that we would like to support'. It is just a matter of contacts, our newsletters go out to various people, one word leads to another and, 'I belong to a service club'. So there is all that information sharing that goes on and networking. Therefore people get to understand the needs at that particular time that you may have.

**Mrs BUTLER** - There is a lot of extra responsibility on your shoulders, apart from your job description?

**Ms BROWN** - True, but then it is the commitment that you make to your school community, isn't it? Then you see the outcomes when students get access to this technology and the huge impact that it has on their personality development, their social development and their access to education and literacy. I brought along a couple of quotes from a little boy who has just been to Victoria to get access to some specialist communication services in this field. He has trialled an electronic voice output device for the first time in his life and his first spoken words were: 'Hi, my name is (his name). Gooday. Thank you, thank you, thank you. I want my communication book'. He was given access to his communication book, which is a low-technology paper-based book, and he used it to devise a message that said: 'Let's pretend', then there was his name, 'can talk'. He was able to say, 'Let's pretend that I can really talk' and then he used his device to make those spoken statements. It is so engaging to see the students respond in that way and the reinforcement that they get from other people in their environment. It is almost like a greater acknowledgment that there is a person in there because they get access to communication that is understood.

**CHAIR** - How old would that boy have been?

**Ms LOVATT** - He is still in early learning. He would be four going on five. His parents are really strong advocates and obviously have gone to Victoria to get access to services and equipment that is not as forthcoming, unfortunately, down here.

**CHAIR** - That is a shame.

**Mr BEST** - In the Victorian thing here it talks about covering repairs and maintenance. In Victoria is it a government thing that they do the maintenance themselves?

**Ms LOVATT** - Yes it is part of the aids and equipment program. The aids and equipment program is the umbrella, the very broad scheme, and then the electronic communication device scheme is a subpart of that larger scheme. They have access to technicians within that umbrella organisation, I believe.

**Mr BEST** - We heard from St Giles yesterday and they have their seeding clinic and those things. It seems that you have been on your own a lot. If a group had come in, maybe there would have been a bit of support of some kind but you have been on your own trying to address individuals' needs without any organisation behind you.

**Ms LOVATT** - And labouring under massive caseloads, it has to be said as well. All of these things that Grace and I are doing now is done after hours and in our own time. So, yes, I understand that better coordination and cooperation would improve our cause.

**Mr BEST** - I can see how St Giles evolved in that regard and what they do and nothing has evolved here other than you battling on your own.

**Ms BROWN** - That is right and having all these contacts, knowing to whom you can go and that this person might help if we go to him.

**Ms PUTT** - It is very reliant on personal networks, there is nothing else there.

**Ms LOVATT** - It is hard to quantify and identify the need because there has not been an effective mechanism for people to get access to what they need and show that they do have the need.

**Mr WHITELEY** - Do you have any idea of the need in this region?

**Ms LOVATT** - It would be just a guesstimate.

**Mr BEST** - There are 420 applications in Victoria.

**CHAIR** - Felicity and Grace, I am going to have to wrap it up here. Your submission was quite comprehensive and thank you very much for the extra notes. I am sure we have all been very interested in this Victorian scheme, which I think is worth investigating.

**THE WITNESSES WITHDREW.**

**Mr STEVE DALEY**, EXECUTIVE DIRECTOR, DEVON INDUSTRIES TASMANIA (DIVISION OF DEVONFIELD ENTERPRISES) AND **Ms MILLICENT SUBONJ**, EXECUTIVE DIRECTOR, MULTICAP, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

**CHAIR** (Mr Finch) - Thank you very much for taking the interest to appear before us today. We appreciate that very much. We will hand over to you, if you care to make a submission to us, and then we will question you.

**Mr DALEY** - Thank you, and thank you for the opportunity to appear before you. We do not have a formal written submission as such but we would like to talk to the national Disability Service submission, which I believe you have already received, and talk about our experiences and how it relates to the north-west coast - and it is a tag team.

**Mrs BUTLER** - That means you will interrupt?

**Mr DALEY** - No, not at all.

*Laughter.*

**Mr WHITELEY** - That is on *Hansard* by the way and you said you were going to tell the truth.

*Laughter.*

**Mr DALEY** - I will be maintaining eye contact with members of the committee.

**Ms SUBONJ** - Multicap provides services for people with fairly profound disabilities and we have a larger facility, a 19-bed facility, where I think 90 per cent of the people have physical disabilities and cognitive and communication disabilities and need some form of communication assistance. We have in the past sought to address that with tools that help people with the communication and we still use those but they are tools that we have made ourselves or the clients have worked on them themselves.

Wheelchairs have always been a really difficult one because a wheelchair for a person with a profound disability can cost anything between \$700 and \$12 000 to \$24 000, depending on their needs. On average the wheelchairs that are provided to people at our services are between \$9 000 and \$12 000. To us that is their legs, their mobility. So it is not something that we just look at, it is fairly serious stuff and it is important that it is correct and applied correctly as well.

We use assessments through St Giles and the hospital. We find the hospital assessments work very well because they are very local. That is fine, you can get your assessment but then finding the money for the client's chair is very difficult. These people are paying 75 per cent of their income, which is only the disability support pension, into their accommodation. So there is not a lot left over for them to purchase a wheelchair.

There needs to be a good assessment process and I believe that is there. You may have a waiting list but it is a fairly good system. The equipment that is fully funded needs to be kept in a library; some record of what that equipment is and to whom it was supplied. When that person passes on, that equipment needs to go back into that library and be reallocated. Unfortunately at this point in time it is not. We tend to sit on equipment that is no longer suitable to us but nobody collects it, nobody wants it. It is a specialised piece of equipment, but it still has its value.

**Mr BEST** - It is really interesting you raise that because quite a few people have mentioned equipment being held onto when it could come back in. Do you have an idea of the value of equipment that might be out there on the north-west coast that could be reused? It is hard to put a figure on it, I suppose.

**Ms SUBONJ** - It would be difficult.

**Mr BEST** - It is not managed though, is it, in a sense -

**Ms SUBONJ** - No, it is not managed.

**Mr BEST** - when it could be and someone else could use it.

**Ms PUTT** - The system is bleeding really.

**Ms SUBONJ** - It is very much so. We asked for a change table, which is around \$2 400, and it was really critical for us to have that. Two ladies came into the service who were dependent on that that change table and Disability Services kept telling us, 'We've got one, it's up here in the north-west', and for six months they could not find it. In the end I ordered one and sent them the bill.

**Mr WHITELEY** - Good on you.

**Ms SUBONJ** - They paid it too. But it is just lost in that system and the system needs to be addressed.

**Mr DALEY** - Can I just come in there with Millicent in relation to the assessment? When it is determined that somebody needs a piece of equipment - and we can use Millicent's example of the wheelchair - there is then the delay of getting it because we have to get money from somewhere. It is interesting to hear the comments from the previous people who gave evidence that it is just ad hoc, it is a mish-mash. It is really by word of mouth. That is how you get out there; there are no real formal links there and that makes it extremely difficult.

Just as an aside, I beg to ask the question: why should a person with a disability, or their family, have to go cap in hand to get money to purchase much-needed equipment to enable them to be active members of our community? We only pay lip service to treating people with disabilities as equals in our society. If we were really committed to that -

**CHAIR** - 'Undignified' was the expression we heard yesterday.

**Mr DALEY** - Yes, it is a great word to use. People with disabilities continue to be treated as second-class citizens and, as I say, we just seem to pay lip service to the equality.

The concern that I have is that a person assessed today for a wheelchair, for example, may have to wait 12 months to two years before they get the wheelchair.

**Mr WHITELEY** - If you have gone from age 10 to puberty, then there is a big difference in what you need, isn't there?

**Mr DALEY** - Exactly. So you then have to go through that process again. There is no logic to it all. I know from my organisation, Devonfield Enterprises, that there is a person who was assessed for a communication board in February 2007. That person is non-verbal and wanted to be involved in the community. Here we are, 14 months later in April 2008 still waiting for a board.

**CHAIR** - You have the sense of frustration, Steve, through your desire to support somebody with their quality of life. Do you get the same sense of frustration with the people you deal with when you go to make the application?

**Mr DALEY** - Yes, in a lot of cases. I understand the predicament they find themselves in because of the limited dollars available. They have to prioritise and we have been unable to find out the criteria for determining the order of priority. That would be of interest to everyone.

**CHAIR** - Because then you are not left guessing or trying to get an understanding of what it is.

**Mr DALEY** - Sure. We all think that the client we are supporting at the time is the number-one priority. But it would be nice to say that these are the criteria you need to assess against to determine where you fit in the priority scale.

**CHAIR** - Why do you think that is not available?

**Mr DALEY** - We do not get it.

**Ms SUBONJ** - We get a letter saying it does not fit with the criteria of the program but you do not know what that is. We had a situation with a family who had supported their son with Parkinson's disease for 14 years at home. They could not longer do that. They had to hospitalise him. The hospital called us and said, 'We are ready to release him; will you take him?' If we could take him, he would need a wheelchair. I said, 'Okay, order the wheelchair and get all that done before he comes'. He was with us for 18 months and it was only when a local member became involved that a wheelchair was forthcoming. It was unfortunate that he died three months after the wheelchair was provided. So there is an empty wheelchair and he had no use of it for 18 months. We were pushing him around in some of the ones we scavenged all the bits off and put one together for him. He fell out of it four times and once he was quite hurt. We were just trying to make do with all the bits and pieces we had. We have become experts at putting wheelchairs together.

**Mrs BUTLER** - There are unused wheelchairs sitting in some places as well.

**Ms SUBONJ** - That is what we are using but now that is sitting there too.

**CHAIR** - Do you have any understanding of the politics of why you would not be given an understanding of the priorities? What is your feeling about that? Why do you think they do not reveal it?

**Mr DALEY** - Because then we might be able to mount an argument to show that the client we have on support at the moment is the number-one priority and they would have great difficulty in arguing against that. We do not know what they have based their decision on, so it makes it very hard for us to come back and argue against that. That makes it frustrating. The person making that decision has very limited dollars so you can understand their not supporting it and why they do not want to make it too obvious what the criteria are.

**Mr BEST** - We attended that public meeting here a little while ago at the Penguin Surf Club and Brett was there. Here we are again, I think you said, with the same faces, the same people and the same topics. I thought you might want to talk about that, given that we are on *Hansard* and the fact that it is back to the future all the time?

**Mr DALEY** - There was a huge turnout and I made the comment that 20 years ago I attended a similar forum and the same comments were being made then as they were 20 years later. The only thing that had changed were the faces of the politicians who were present.

**Ms PUTT** - So you are briefing each new politician but nothing was coming out the other end?

**Mr DALEY** - Nothing has changed. Everybody is saying, yes, we understand your concern, it is serious and we need to do something, but we needed to do something 20 years ago. Here we are today, 20 years later, and still nothing. We still have to same problems. In fact they are worse because we are getting more and more people out there with disabilities. I think it is absolutely disgusting in the society in which we live that people with disabilities still have to go cap in hand to raise money some way or another to enable them to purchase much-needed equipment to enable them to be active members in the community, something that you and I take for granted every day.

**CHAIR** - Steve, that meeting that you went to, was that about the issues that are contained in our terms of reference?

**Mr DALEY** - It covered a whole range of things, Kerry. It included access, lack of services, transport and a whole range of things.

**Ms SUBONJ** - There was a very strong point made by a lot of the family members that they want to look after their son or daughter at home. There was a story about a young lady, the daughter, and to get the bathroom, the lift and the chair modified, because she was a growing child, was just horrific. She just could not keep going through that. Apart from the cost of incontinence aids and the cost of equipment, she was working to keep this child at home - saving the State a fortune. The State really needs to look at its priorities and see that these parents are saving them so much money and so it should help them out



with these little things. I am not even opposed to the family or the client making a contribution towards it, a small contribution to show a commitment to caring and being responsible for the equipment. At the end of their need there could be a small rebate based on the period of time they have had the equipment.

There needs to be a quick response, because the quick response keeps them motivated, moving forward and wanting and able to develop their abilities, because once you lose that muscle tone lying in hospital waiting for a wheelchair, then you have lost it; it has gone.

**Mr DALEY** - And the pressure it is putting on other members of the family. It is enough having to raise and support your son or daughter with a disability, and the emotional pressures at home, without having to be burdened with -

**Mr WHITELEY** - Having to go and raise money or staying awake at night working out how you are going to get it.

**Mr DALEY** - Exactly. Peg asked the question of people who earlier gave evidence whether they have any indication of the number of people on the north-west coast. I really do not know and I do not think anybody would have a true indication because if somebody pulled out a figure and said, 'It's 50', I would bet my bottom dollar that it would be double that because there are a lot of people out there who are absolutely frustrated that they are not getting any assistance whatsoever. They are sick and tired of the red tape, the continual knock backs, so they just walk away.

**Mr WHITELEY** - So it now becomes an unmet demand that we cannot even quantify.

**Mr DALEY** - And which is going to cost more in dollars and human suffering.

**Mr WHITELEY** - Steve, what would you say to evidence that was given recently that suggested that the waiting list for the Community Equipment Scheme in total for every region was only \$609 000 and it only involved 187 people?

**Mr DALEY** - They must not be talking about the State of Tasmania.

**Mr WHITELEY** - I think that goes to back up what you are saying. That is the official list of the people that have been gutsy and courageous enough to stick with it because the rest have just said 'blow it'.

**Mr DALEY** - Yes, and I can understand that. Millicent and I in different forums would argue the same when departmental people refer to waiting lists for other services. They say, 'We only have  $x$  number of people waiting for respite or  $x$  number of people waiting for accommodation'. That is true. I do not argue with the figure that they have but that is the people who have put in an application. However, we know there are a countless other people out there. Not far from here is a family who just gave up hope a few years ago. They have two children with disabilities and they just have no service whatsoever because they got sick and tired of banging their head against a brick wall the whole time. They decided to put all their energies into raising the son and daughter without having to battle the bureaucracy. So there are those people who do not go on a list because they are no longer putting in the application for service.

**Mr WHITELEY** - We do not have a clue, do we?

**Mr DALEY** - I do not think we have. In any of these situations, Brett, I do not think you will ever get an absolutely accurate figure.

**Mr WHITELEY** - But we are nowhere near it, though, are we?

**Mr DALEY** - I do not believe we are anywhere near it.

**Ms SUBONJ** - When you are told often enough that there is no money you tend to give up.

**Ms PUTT** - Are you starting to see any impact from the \$800 000 that has been injected from the Federal Government?

**Ms SUBONJ** - We have not as yet, no. We are doing probably four assessments and we are hopeful that those assessments will meet the funding criteria.

**Ms PUTT** - Whatever they are.

**Ms SUBONJ** - We have put in applications and are getting some assessments done.

**CHAIR** - A question in respect of equipment. We heard, yesterday, in Launceston, that there is a pool of about \$6 000 a month. Do you have any understanding of what it is for this region?

**Mrs BUTLER** - That was for the north.

**CHAIR** - So it would be similar, I would imagine, in the 63 telephone district?

**Ms SUBONJ** - That smaller sum would be for handrails, hand-held showers and maybe some non-slip floors or repairs and maintenance or just upgrades.

**Mr DALEY** - \$6 000 is a big of a joke, isn't it?

**CHAIR** - Imagine being on that committee, trying to allocate that money.

**Mr WHITELEY** - You are a practical guy. You have been around a bit. You are an outcome-driven person. How would we, as a committee, find out what is accurate? You said that we could never find out, but how could we get a much better idea of what the need is out there? How could we practically do it? Do you run ads on the TV and put 1800 numbers up? How are we going to get this data to find out what is out there?

**Mr DALEY** - The danger is, once you starting asking that, it gives the impression to people out there that there is more on offer. Somebody could at least write to every service provider in the State and ask them to give some indication. That is a start.

**Mr WHITELEY** - But we are going get a duplication because there is no central register.

**Mr DALEY** - But that, at least, will give you a start. Millicent and I know other service providers constantly faced with this dilemma. If we go out and talk to individuals and families and other organisations about the services we provide then we build an expectation in one's mind that the service is out there. We can say we provide respite services. Millicent can say she provides respite services and next week we get a phone call from somebody saying they need some respite and we say, 'Sorry, we are fully booked for the next 12 months.' But here we are promoting that we have a service. So you have to be careful how you do it.

**Ms SUBONJ** - Our daytime support services are basically full. If we talk to people about what we do and how we do it and how wonderful it all is, they come straight to your door and ask, 'How do I get my son in here?' You have to say that you have to go through Disability Services. Disability Services say there is no funding at the present time, and of course I cannot take you for free. I cannot take them without funding because I have to put staff on to support them. So it is very difficult to promote what you do if you do not have the backup to do it.

The same thing applies with equipment. If you say there are equipment schemes being funded and I send a little sentence out in the newsletter, then I do not make it a big deal that the Government has provided \$855 000 for equipment. I know that a lot of that is already booked up. It is fine to say that they only have applications for \$650 000 and there are only 187 people wanting it. That is this year. That is current. There will be people next year and the year after. As I understood it, the \$855 000 is for this year.

**Mr WHITELEY** - It is a catch-up thing.

**Ms SUBONJ** - It is a catch-up. What is going to be there for next year?

**Ms PUTT** - Is there any relationship between people not being able to get appropriate equipment and the need for respite?

**Ms SUBONJ** - From the family's point of view, the less equipment they have and the less aids and support they have, the more they depend on respite.

**Ms PUTT** - So we are not just talking about the deterioration of someone's condition and then perhaps their needing to be in a much more expensive mode of health care. We are also talking about the cost and provision of respite. I am not saying people should not have it but there could be a positive impact for respite if people had more ready access to the equipment they need.

**Mr DALEY** - Yes, you are right. We are not really talking about the impact it has on the person with the disability, it is the impact it has on their family.

**Ms PUTT** - Yes.

**Mr WHITELEY** - We heard yesterday about the impact on the care workers of the OH&S. If you do not have the right equipment then the carers, and often even family, are going to be doing their backs in.

**Mr DALEY** - Why should organisations like Multicap and Devonfield have to raise money for much-needed equipment because we cannot get the funding from government to enable us to support a person buy a hoist? If we do not get it, we put our support staff at risk of injury.

**Mr WHITELEY** - They will spend time travelling across town.

**Mr DALEY** - Then of course if they are injured, the workers compensation costs go up, you would think.

**Mr WHITELEY** - Mike Sertori from St Giles put that very issue to us in this way: who has sat down and actually done a cost-benefit analysis? If you want to talk in purely economic terms, then Peg is right. I would say the link is definite; we have a link to respite, we have a link to OH&S. Goodness only knows where the links stop.

**Ms PUTT** - We have a link to institutionalisation.

**Mr WHITELEY** - Yes. As you said earlier, if suddenly every carer, parent and the family of a person with a disability went on strike and said, 'Sorry, we don't have to do this, over you go', imagine what is going to happen.

**Mrs BUTLER** - I think they threatened that during the Liberals' reign.

**Mr WHITELEY** - They may have, I do not know.

**Mr DALEY** - It would be interesting, just as an aside, to conduct an exercise to see how many young people with disabilities are inappropriately placed in nursing homes and would be out in the community if the equipment and support were provided.

**Ms PUTT** - That is interesting.

**Mr DALEY** - Because there are a large number of people inappropriately placed in nursing homes.

**Ms SUBONJ** - We do occupational health and safety and manual handling training for our staff - we bring it on every year - and in the last session I belatedly rang a few of the family members who look after their sons and daughters at home and said, 'Would you come in and sit through this training session? You might get something out of it'. The few that came said it was brilliant and that they had been doing it wrong all this time. I know how much it takes out of my staff and they only work probably 40 hours to 60 hours a fortnight. These parents are doing it day in and day out, 24 hours a day, and they have no assistance other than the person who comes in for an hour in the morning and maybe an hour in the afternoon. Their backs have got to be gone.

**Mr WHITELEY** - Shot.

**Ms SUBONJ** - Shot, and without that equipment they will depend on respite, they will depend on all sorts of things - family, friends, brothers and uncles - it is hard. So equipment does mean a lot.

**Mrs BUTLER** - You mentioned that you get some of your assessments done at the hospital.

**Ms SUBONJ** - Yes.

**Mrs BUTLER** - Can people from outlying areas also get that?

**Ms SUBONJ** - We get it because we kick up a bit but I suppose families can get it too.

**Mr DALEY** - Although, Heather, you would probably get it much quicker through the hospital than with Disability Services.

**Mrs BUTLER** - And you have the appropriate personnel to do it in Burnie?

**Ms SUBONJ** - Yes.

**Mr WHITELEY** - Would you agree, though, that there is a shortage? We had evidence yesterday suggesting that there was a pretty drastic shortage of OTs and physios.

**Ms SUBONJ** - Yes, absolutely.

**Mr WHITELEY** - Brenton, was it you who asked a question and they said one of the recommendations ought to be that we should be getting back to training in the State?

**Mr BEST** - Yes. It is interesting that we do not seem to have any trouble getting an OT to visit a housing constituent but they cannot get anything done. They visit and do the report but we cannot get anything done to the property.

**Mr DALEY** - Are we allowed to ask the committee members questions?

*Laughter.*

**Mr DALEY** - I think we need to get back to providing the opportunities in this State for OTs, speech pathologists, physios, et cetera, because there is a dearth of them; they are desperately needed.

**Ms SUBONJ** - We are even using the Medicare allied health professionals who have come through the Federal funding. But getting a doctor to prepare the extended care plan that is required to access that is a small nightmare too. The doctors are run off their feet so it is really hard to get that organised so that you can use that facility, but we do.

**CHAIR** - We need to conclude, but we will give you the opportunity to make some last comments.

**Mr DALEY** - I was going to make my final comment to the committee - and once again, thank you for the opportunity to appear before you - that if you really are, like we all should be, committed to equality, let us not just pay lip service to it. I would like to see something from the report of the committee's inquiries showing that equality is not lip service; we really have this firm commitment to doing something.

**CHAIR** - Millicent?

**Ms SUBONJ** - No, I say 'Hear, hear'.

**Mr WHITELEY** - Just for clarification, and not for any political hit, the position of the committee is to take the evidence, across party lines, across both upper and lower Houses - and we work well together - to put a report together with recommendations and at the end of the day that is passed on through the Parliament, tabled and the minister will have the responsibility to read that report and take it on. We will do our best as we take the evidence and we will report it correctly and accurately but we do not make that decision.

**Mr DALEY** - We appreciate that and we appreciate the interest the five of you are showing in the difficulties confronting people with disabilities and their families. If you can put in a strong report, it just adds weight to the argument by this sector that we have been waiting in excess of 20 years for something to be done.

**CHAIR** - Thank you very much.

**THE WITNESSES WITHDREW.**

**Ms DIANE EWINGTON**, FAMILY ADVOCATE/SUPPORT WORKER, ASSOCIATION FOR CHILDREN WITH DISABILITIES, AND **Mr GORDON PATCHIN** WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

**CHAIR** (Mr Finch) - Thank you both for attending. I do not know your role or where you are from so you might explain yourselves first of all. Diane, do you want to putting a verbal submission to us this morning?

**Ms EWINGTON** - Yes.

**CHAIR** - Thank you. Gordon, you will join in and supplement where you are able to.

**Ms EWINGTON** - I was not aware of this until I read yesterday's *Advocate*. I work for the Association for Children with Disabilities. I am a family advocate and support worker. I have worked there for five years. I have a daughter who is 20 who has a severe and profound disability so from the time that she was five months old I have been actively lobbying for better services for families with disabilities on my own behalf and for other families. My daughter was born without eyes, which obviously makes her blind. We thought she was just going to be a blind girl but she is practically non-verbal, is unable to walk without assistance and is incontinent. She is ours and we are determined to keep her at home for as long as we can while we get the assistance that we can.

Today I am here to represent and speak for other families who are not able to do so. I am quite able to speak for my own daughter and our family.

The overall deficit that families find is in the assistance with incontinence aids. Practically every family who has a need is spending \$2 000 to \$3 000 at least in a year. The allocation for that from the Government is about \$400 or \$500 so most families are spending a huge amount - and incontinence aids are just the initial outlay; there is all the hygiene equipment that is added on to that which is an added cost so families are looking at a huge cost. Nine families that I know of would be spending that amount.

**Mr WHITELEY** - That is \$3 000 or \$4 000 a year?

**Ms EWINGTON** - Yes. That is not covered by the disability support pension.

**Mr WHITELEY** - So you have a gap. Let us say it is \$4 000 and you get \$400; there is \$3 600. Does that fit into the category where, if you are earning income and paying tax, you can claim that as medical expenses over the \$5 000 or whatever it is?

**Ms EWINGTON** - No, not that I am aware of.

**Mr WHITELEY** - I am not saying that will fix your problem but I am just interested to know because we had taxation raised yesterday as an issue.

**Ms EWINGTON** - I do not know. I suppose, try it and see.

Sometime last year I was contacted by a family who had a child born with severe brain injury and I became involved when it was made known to me that there was equipment that had been ordered particularly for that child. The child was a patient at the hospital. He was about 18 months at that stage. Equipment had been ordered that would assist the family to feed him, allow the family to access family visits while they were in the hospital - the child was a permanent patient in hospital - and allow the family to take him home for short stays. The mother was spending every day in the hospital, travelling 60 kilometres every day. She had two children at home. Her partner needed to work part-time to manage the other children and she was often required to stay overnight because his health was very precarious.

The equipment, as I said, was ordered, was available. It was not made available to them until they could pay over \$6 000 for it. It was locked up in the storage room at the hospital. When it was made known to me I was able to find a service club. I put a submission in to them, they provided that equipment and that child and that family were able to have a small measure of normality, as much as they were able to. It had been in the hospital for six to nine months. This little boy had use of it for three months before he died. He was an absolute, severe epileptic. I can give you family names if you need verification.

**Mr BEST** - That is okay.

**Ms EWINGTON** - It was a piece of equipment that would help him to sit upright so that he would be able take in food and also the morphine drip. He was on an immense amount of morphine. It could be adapted so that he could be put into a pram and wheeled around the hospital so they could get out of the ward and they could also take that equipment and put it in the back of the car as a car seat for a child with a disability and go home for short trips. It would have made an enormous difference to that family.

**CHAIR** - Diane, was the equipment bought especially for that child, did you say? I missed that bit.

**Ms EWINGTON** - Yes.

**Mr WHITELEY** - It had to be paid for by someone.

**Ms EWINGTON** - It had to be paid for. The hospital did not have the budget to make it available.

**Mr WHITELEY** - But who paid for it to get it?

**Ms EWINGTON** - It came from New Zealand and it had not been paid for.

**Mr WHITELEY** - I am aware of that case.

**Ms EWINGTON** - It was about to be sent back to New Zealand because the manufacturers could not wear the cost.



**Mr WHITELEY** - So it was bought on invoice and stayed in the storage room until a service club raised the money and that child could have had that for six months more than he did before he died?

**Ms EWINGTON** - That is right.

**Mr BEST** - What happened to the equipment afterwards?

**Ms EWINGTON** - It was bought on the understanding that if it was no longer needed it would go to the Community Equipment Scheme, and we had spoken to the physios and OTs up there. It would definitely have a use within this community on the north-west coast. It was not something that would be ordered to have a one-off need.

**Mr WHITELEY** - It might have sat there again but at least it was there for someone?

**Ms EWINGTON** - Yes. So now it has gone to the Community Equipment Scheme. I am not sure -

**Mr BEST** - If someone has used it, but it is there?

**Ms EWINGTON** - Yes, it is available for someone to use and certainly the family were happy with that. There was no issue with that at all.

**CHAIR** - Diane, do you have an understanding of where this equipment is kept? Is there a special room at the hospital? Where does the community equipment go?

**Ms EWINGTON** - No, I don't know.

**CHAIR** - I suppose that is the idea; keeping a track of it, isn't it? Where is it when you need it?

**Ms EWINGTON** - It is very interesting. I have another family who had access to equipment while their daughter was at school. The child, again, was severely disabled, had to lie on her side because she needed to be out of the wheelchair. She had severe scoliosis but it was made and moulded to this particular person's body shape. It was a sideliner, and two pieces of equipment were made particularly for this child. Once the child leaves school it has to go back to the Community Equipment Scheme. Now that she has turned 18 she goes to a day-service program and she cannot take that piece of equipment with her because it is specifically for 18s and under and it is for school.

**Mr WHITELEY** - Even though it is still okay for her?

**Ms EWINGTON** - Yes, and it is not available for anybody else because it has been made to her body shape. Wherever the Community Equipment Scheme is, it is in their store room.

**Mr WHITELEY** - So once you get to 18 and are not in the education system you fall outside the loop?

**Ms EWINGTON** - Apparently.

**Ms EWINGTON** - As I said, the day-service program cannot afford to have it made again - it costs thousands.

**Mr WHITELEY** - It had to be given back?

**Ms EWINGTON** - It has to be given back.

**Ms PUTT** - And it is sitting somewhere not being used because it is only appropriate for her?

**Ms EWINGTON** - Yes, only appropriate to this person.

**Ms PUTT** - If there was ever a definition of 'bureaucratic nightmare' I think we have just discovered it.

*Laughter.*

**Ms EWINGTON** - I could give you the name of that person.

**CHAIR** - We will need to follow that one up.

**Mr PATCHIN** - A similar thing happens during school holidays. The equipment they can use at school they are not allowed to take home and use during the holidays - things like that.

**CHAIR** - What is the thinking behind that?

**Ms EWINGTON** - It is a scheme that is available to the Education department within the school but it cannot be used for families at home, so it has to be duplicated if you need it at home and families have to buy what is then needed at home. I have been in that situation myself. My daughter needs a stroller; she doesn't really need a wheelchair. It costs about \$2 000 and luckily the physio department was able to access one for us. For a long time we used a stroller that was not suitable but she had the equipment that was needed at school, but we were not allowed to bring it home. The school would let you -

**Mr WHITELEY** - So you can take a guitar home for music?

**Ms EWINGTON** - Yes.

**Mrs BUTLER** - Is it about insurance?

**Ms EWINGTON** - It is purely to be used in an educational setting.

**CHAIR** - Is that viewed as unreasonable and bizarre?

**Ms EWINGTON** - It is, yes. The other family I have had two children with a disability. The husband has a work-related injury which means he cannot work. The house is very old. They own it themselves and they own a lot of land around the house. One child has an autism spectrum disorder and does not really need any assistance, but the youngest child

has severe cerebral palsy. She is only 18 months old. The house is not suitable for any adaptive equipment because there are steps. It has been added to; it is an old farm house.

They have had the OT department to have a look at the house but there is very little that they can do with that house to adapt it to this child. The family would be prepared to sell the house they have, subdivide the land and build an adapted house next door. They really cannot afford it without selling the land, but because of not being able to sell off parts of your land in a rural area they have not got that capacity, so they are in a quandary about what to do. They cannot afford to move out because the husband is not working. They like the area and the child with autism spectrum disorder needs to go to the same school. They know that they will have huge issues with equipment as she gets older, and accessing that equipment again is hit and miss. Again, a squeaky wheel will get the equipment.

**CHAIR** - When you say she needs to go to the same school, is that for her own wellbeing?

**Ms EWINGTON** - Yes, it is preferable. The family feels that it would be better. The requirement for her to maintain that same school environment is greater at this stage than their need to move house because of the younger child's physical disabilities. The child is manageable but they will need a hoist, tracks and wider doorways. The assessment from the OT department says that this house is not suitable for that so she has no idea what they will do. She asked me to mention that. I do not know what the solution is. She was wondering whether there was any government assistance to relocate or to do major modifications. The recommendation was that they would need to bulldoze that house because it is just so far away from being suitable.

**CHAIR** - Is that person from the Burnie area?

**Ms EWINGTON** - Yes, she lives in Elliott.

I have another family, a single dad with a son who has a degenerative disease. They have spent an enormous amount on a wheelchair-accessible van for this boy. He has grown to the point that he has to duck to get into the van now. To get a new van is going to cost about \$50 000 and they cannot really afford it. He is a farmer so he is asset rich but his income is probably not so good. The child could stay at home - he is transported to and from school so that is okay - but how many times does he need to buy another van and fund it for himself. He is asset rich and does not fall within the criteria to get assistance, but I do not know if there is any assistance for wheelchair-accessible vans. So that is another family with difficulties. I think the only alternative for this family is to take the roof off and try to get some kind of extension to the van and put the roof on again, but again it is quite a significant expense.

**CHAIR** - When you say the child gets to school okay, is there a bus that comes to the door?

**Ms EWINGTON** - Yes.

**CHAIR** - How does he get on and off the bus?

**Ms EWINGTON** - It has a hoist. It is a bus attached to the support school. He does not go to the support school but -

**CHAIR** - The bus still picks him up?

**Ms EWINGTON** - Yes, picks him up and takes him home. There is probably a lot more that I could say but I have not spoken to other families.

**CHAIR** - It is still not too late. If they want to, or you on their behalf, write to us we will still take that into consideration.

**Ms EWINGTON** - The family with the house is also waiting for a Hart walker for their daughter to enable her to walk. For children with cerebral palsy it keeps them upright; they just need to move their legs. There is a 12- to 18-month wait for that particular thing for this same family, but with steps in the house there is only a short distance that this person will be able to walk

**CHAIR** - So what would the cost of that piece of equipment be?

**Mr PATCHIN** - At least \$6 000 these days.

**CHAIR** - Is it motorised?

**Mr PATCHIN** - No. It is basically just a frame. You strap the child in and it allows them to stand up and use their legs. It stops inappropriate movement of the legs so that children who tend to scissor their legs cannot do it. They can use their muscles; it sort of trains the muscles.

**CHAIR** - It is expensive though, isn't it, \$6 000?

**Mr PATCHIN** - We had ours several years back and we do not have it any longer. We were told at the time that once the child grows out of it, it is no longer suitable for that child but they cannot reuse it, which seemed a bit strange to us. I do not know what happens to them after that.

**CHAIR** - So what happened to the piece of equipment that you were finished with?

**Mr PATCHIN** - We returned it to Cerebral Palsy Tasmania and I do not know what has happened since then.

**CHAIR** - Was there then an upgrade for your child?

**Mr PATCHIN** - No, we have since raised money and have bought ourselves a new walker, a different style of walker. We did not bother trying to get funding for it because we know what the situation is. There is such a limit on the amount of funding available so we went out and purchased one.

**CHAIR** - So what was the cost of the replacement equipment?

**Mr PATCHIN** - It was another \$6 000 roughly.

**Mr WHITELEY** - If I could take the liberty, I have some notes that I took from Gordon's partner in relation to that matter and this summed it up. I think it is really important because this is how people are so connected by all their challenges. It says that a child needed a new chair but how could we ask when we know there is a little boy in Smithton, as advertised and promoted in the paper, and other kids who do not even have a basic chair. So we have a situation now where we have people who are desperately in need themselves but who sense that there are other people in deeper need and so do not enter the system. That is where we are.

**Ms EWINGTON** - A lot of families do that in regard to respite. They say, 'I can manage and I know that there are others who are worse off. I do not like to be a burden'. Everybody has a need for some respite.

**Mr WHITELEY** - Special shoes are required for some children; is there any coverage for them in the Community Equipment Scheme?

**Ms EWINGTON** - No.

**Mr WHITELEY** - There is nothing for them?

**Mr PATCHIN** - I would imagine that, if you put an application in to the Community Equipment Scheme, once funding became available for it you might get it.

**Mr WHITELEY** - There is nowhere in the list at the moment?

**Ms EWINGTON** - I heard about it years ago when my daughter was born because she did need shoes. We did not receive them. I do not know anything about it and I do not know anybody else who knows about it.

**Mr WHITELEY** - They can be \$400 to \$500 a pair and you need two or three pairs. You know what kids are like, they grow out of them pretty quickly.

**Mrs BUTLER** - I think there is some help through the Sunshine association.

**CHAIR** - Gordon, did you want to present a story to us?

**Mr PATCHIN** - Not particularly. I did not really know this was on until yesterday. I prefer to put my voice to what has been said so far since I have been here. I totally agree that lack of funding and availability of equipment is big problem. We do not feel that we should be asking for more because we know there is such a limit out there and there are other people that need it. We feel certain amount of guilt in asking for more funding. I feel that our family is a bit lucky in that we can afford to buy things ourselves to a degree. We refinanced our house recently, borrowed \$50 000 on it to re-do our bathroom and put in new hoisting and everything. That is just the way things are.

**CHAIR** - So that was something that you did for your child without assistance or a partnership with the CES or without any State Government assistance?

**Mr PATCHIN** - Yes, we just went in and did it ourselves, partly because we know that if you do apply for funding you would wait a long time. We are getting a new chair fitted

at the moment for Jessica. We have been talking about it for the last two years. We had put the wheels in motion about two years ago and it has finally arrived. We have not applied for anything since that chair a couple years ago.

**CHAIR** - Did you get some assistance with the chair?

**Mr PATCHIN** - Yes.

**CHAIR** - To what extent - the full cost?

**Mr PATCHIN** - I think we had to pay a \$50 fee towards it.

**Ms PUTT** - Oh yes, we heard about that \$50 fee.

**Mr PATCHIN** - Which is fine. It seems awfully cheap, really.

**CHAIR** - So what is the cost of the chair?

**Mr PATCHIN** - It would be \$6 000 or \$7 000, something like that. The seating clinic from St Giles was here this morning measuring it up so there will be costs involved in getting the seating for it as well.

**Ms PUTT** - When you applied for the chair I do not suppose you expected that it would take two years.

**Mr PATCHIN** - Well, I sort of figured it would take a while. Having gone through the system a few times now, we know that we are going to be waiting a long time so we started early on this.

**CHAIR** - How old is Jessica now?

**Mr PATCHIN** - Sixteen.

**CHAIR** - Yes, the time has flown and of course that is the other issue, too; it is constantly changing and adapting as they grow.

**Ms EWINGTON** - From my understanding, with that sort of equipment you have to get as much done as you can while they are still at school or while they are under 18 because once they become adults the cost is so much higher.

**CHAIR** - Why is that, Diane?

**Ms EWINGTON** - I don't know. Once they turn 18 you cannot access OTs and physios. There is no speech pathology made available. You are able to get physio service if you go through the allied health initiative from the Federal Government but it is not routine that physios or OTs come to the day service to have a maintenance or even a consultative process. You can access as you would, I dare say, a normal member of the community if you have an issue but often as parents we do not see that the issues have arrived; we see this child as it is and we are not always aware that they are doing something worse than they used to or there could be some equipment that could help - it could be shoes or

orthotics - and again the cost of that once they become adults seems to be higher than at school age.

**Mr PATCHIN** - We are not sure what is going to happen when she turns 18. Up to this point a lot of the things that we have needed we have been able to get through the hospital in one way or another and we had good access to the physio and OT through school from the hospital there. We have had orthotics over the years and we just make an appointment to go into the orthotics department in the hospital and it is taken care of. I am starting to worry now because once she turns 18 it will be difficult.

**CHAIR** - Whom would you turn to for advice and guidance there? Is there somebody at the hospital who would guide you through there?

**Mr WHITELEY** - Diane.

*Laughter.*

**CHAIR** - Keep brushing up on the latest information, Diane.

**Ms EWINGTON** - I just need to be a few steps ahead.

**Mr PATCHIN** - I guess another thing is that once Jessica turns 18 we do not go to Diane any longer. ACD only takes care of children.

**Mr WHITELEY** - We expect it will be hard to find out where these young people and older people are, where this need is that is obviously greater than we would think. Do you keep a pretty detailed database of your contacts? Have you got their names and their strategy for the next 10 years?

**Ms EWINGTON** - No.

**Mr WHITELEY** - No?

**Ms EWINGTON** - That is how it should be. Obviously these people are born into this community and yet every year as the child gets to 16 and is looking at where to go next, the rigmarole that we have to go through to get funding made available for them to access the next service, which is a day-support program, supported work or whatever. It is not as if anybody budgets, knowing that that person is in the community.

**Mr WHITELEY** - They know that if someone today is one year old, they are going to be 16 in 15 years' time, don't they.

**Ms EWINGTON** - Yes, and in another 10 to 15 years on top of that it is highly likely that these people are going to need a group home or something like that.

**Mr WHITELEY** - Because mum and dad will be a bit too old or whatever.

**Ms EWINGTON** - There is not even a waiting list. Disability Services refused to even have a list because if they had a list and it is written down then they might be held accountable. There is nothing they can do; they are not getting the funding at all.

**Mr WHITELEY** - It is a big issue.

**Ms EWINGTON** - I try to find out as much as I can, through my contacts through Grace from the support school and through the regular schools, about where families are and what they need to do to access the next service because it has to be family driven. If families do not do something, nothing will come to them. No-one will come and knock on your door and say, 'This is what you need'.

**Mr WHITELEY** - Let us say that a baby is born at the Burnie hospital today and in the next 12 months is diagnosed with a severe disability, cerebral palsy or whatever it is. Every child is different and every case is different. However, it is pretty predictable. Let us be frank, it is fairly predictable, with a few little ups and downs in the middle. So it is possible that child, unfortunately, is going to face these challenges. But it is possible to map a 25-year life plan for Jane, straight through, that is going to say, 'Mr Government, over the next 25 years, building in an inflation rate, this and this, these hundred things are going to happen and the cost for this child will be \$275 000'. That is possible?

**Ms EWINGTON** - It is possible, yes, and you could access that information through the paediatrician at each hospital because the paediatricians will be probably the one constant in that family for quite a number of years. Some children do not need ongoing medical treatment but there is always a requirement for some kind of referral because there are always issues that parents are not aware of. I have been in situations myself where I have turned up for just a regular check-up and found out that there are huge issues that we had no idea that we were dealing with.

**Mr WHITELEY** - But it is possible that just with good intention and a process and a plan, we could get that. That is where we have to get to, don't we?

**Ms EWINGTON** - Yes. I am even more diligent because since my daughter was born, probably about 10 years ago I came home one day and there was a huge number of police, ambulance people, people in suits, all kinds of people in our street. They seemed to be directed to a house across from me and up. I had no idea what was going on. We had been there probably 15 years at that stage. In that house was a 40-year-old woman who had lived there with a severe disability all the time that we had been there. The mother had had a stroke and had been moved out. The ailing father who was in his 80s was there looking after her. He had absolutely no service at all. She was incontinent. She was kept in one room of the house. Apparently it was in a disgusting state, as you could imagine, and I did not know that she was there. She was contained in the front room of the house so she would be able to see the street. Family members were not encouraged and were never allowed in.

To think that that woman had lived there all that time in that state with the father not able to even address her hygienic needs, nor probably her nutritional needs. She has since been moved to quite a good residential area and has developed skills that no-one ever knew that she had because she just did not have the opportunity. It was a house that had lots of steps. They were not able to get her in and out. I did not even know she was there.



**CHAIR** - But we have this other example from Germany with the father and his daughter who was kept in a dungeon for 25 years.

**Ms EWINGTON** - Yes, that is right.

**CHAIR** - Is there anything more that you would like to add, Diane or Gordon, in conclusion?

**Ms EWINGTON** - As I said, I started doing these things when Emma was six months old and I have been doing them ever since. There have been surveys, I have lobbied and have assisted in getting paediatric OTs and physios that were not here. We just hope that something will come of it and that is why we keep coming to the powers that be who have the ability to change things and who will listen to the parents and hear what their needs are. We hope that something will be changed sometime. Thank you for the opportunity.

**CHAIR** - Gordon?

**Mr PATCHIN** - I agree with everything she says. There is a real problem. I think if the assistance was made available, you could find people coming out of the woodwork and saying, 'I didn't even know this was available so I've never known to ask for it'. We find it with equipment; they will suddenly see some piece of equipment and think, 'Gee, I could have used one of those' but they did not know it was available.

**CHAIR** - There is not good communication out there and partnership with the bureaucracy, for the want of a better word, in guiding you and helping you and partnering you through your trials and tribulations. Thanks very much, Gordon and Diane.

**Ms EWINGTON** - In the five years that I have been doing this job, I would say that I have come across five or maybe eight families who have decided that they cannot do this anymore. They have relinquished their children into family care. They asked and were not able to access the assistance that they needed, and of course that is a huge cost to the Government. I understand group homes cost \$100 000 -

**CHAIR** - Yes, \$100 000 per person.

**Ms EWINGTON** - And then there are day service programs after that. These kids were all under the age of 10 and that is a huge emotional cost.

**Ms PUTT** - That is right. It is not just the actual dollar cost.

**CHAIR** - And you are suggesting that given the support they would have retained their children at home?

**Ms EWINGTON** - I cannot say that they would retain them forever but I am sure it would have -

**Mr WHITELEY** - For a lot longer.

**Ms EWINGTON** - Yes, a lot longer. They certainly had an emotional connection. They love their kids and they wanted to keep them but they found that it was overwhelming and they felt that they were not able to provide the best for their children.

**Mr WHITELEY** - And we should not sit - and you are not - in judgment of that decision that they make.

**Ms EWINGTON** - No, it was not their first choice but they decided in the end that it was best for their children and that their children would be better off with other people caring for them.

**Mr WHITELEY** - This is the cost-benefit analysis that Mike Sertori was talking about. It is all very well to say now that it costs too much money when we compare it to what it might cost.

**CHAIR** - Diane and Gordon, thank you for being patient with us.

**THE WITNESSES WITHDREW.**