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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

MS P. SCOTT, Presiding Commissioner
MR D. KALISCH, Commissioner
MR J. WALSH, Commissioner

TRANSCRIPT OF PROCEEDINGS

AT HOBART ON MONDAY, 7 JUNE 2010, AT 10 AM

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MS SCOTT: Good morning, welcome to the public hearings of the Productivity Commission inquiry into Disability Care and Support. This is our first day of hearings and thank you for attending today. My name is Patricia Scott and I am the presiding commissioner of this inquiry. My fellow commissioners are David Kalisch and John Walsh coming through from Sydney.

This inquiry started in April with a reference from the treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, costs and benefits of a national disability scheme that would provide long-term essential care and support, manage the cost of long-term care, replace the existing funding for those people covered by the scheme, take account of the desired and potential outcomes of each person over a lifetime with a focus on early intervention, provide a range of coordinated support options, including accommodation, aids and appliances, respite, transport, day program and community participation, assist people with disabilities to make decisions about their support, provide for people to participate in education, training and employment where possible.

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and other approaches used in other countries. We have already talked to a range of organisations and individuals with an interest in the issues and submissions have been coming into the inquiry following the release of an issues paper in May.

We are grateful for the submissions already received and submissions can be downloaded from our web site www.pc.gov.au. While we would like to get submissions as early as possible in view of the concerns raised by some participants, the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission also welcomes second or even third submissions and fourth after the due date for the initial submissions. These submissions may include additional points you wish to make, comments on other people's submissions and the results of community consultations.

The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on a public record. Following this hearing in Hobart and, depending on demand, hearings will also be held in all capital cities commencing today and then going into July. We will then be working towards completing a draft report in February next year for public comment and we will invite participation and another round of hearings after interested parties have had time to read our draft report.

We would like to conduct all hearings in a reasonably informal manner, but I remind participants that a full transcript is being taken. For this reason, comments from the floor cannot be taken but at the end of our proceedings, around lunchtime today, I will provide an opportunity for anyone who wishes to make a brief comment. Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on the issue raised in other submissions. The transcript will be available from the commission's web site following the hearings. For any media representatives attending today, some general rules apply. Could any members of the media please raise their hand now. No media, thank you. If we do have any media, we just ask them to be cognisant of people's right. I would now to welcome Roger Law to come forward.

MR LAW (ATAC): Thank you.

MS SCOTT: Roger, could you just identify yourself for transcript purposes and your organisation and then would you like to provide an opening statement.

MR LAW (ATAC): Yes. My name is Roger James Law. I am the secretary of Action for Tasmania's Autistic Children and we put in a major submission which - I will apologise straightaway - we were intending to wait until after the major meeting for autism researchers in America in Philadelphia which finished last week before we finalised any submissions and when we realised you were coming to Hobart, I was told to get it done immediately. We would have had a lot more in it if we had had the time and we probably will accept the offer of putting in something later.

I have seen on the web site a lot of the problems of people who have and are looking after and caring for disabled children. Just to put it in perspective, sometimes they can give you enormous pleasure. Last night my 13-year-old autistic grandson, after he had been on Facebook for an hour, came in to me and said, "Grandfather, what's gay mean?" So I of course said, "Jolly, happy," so he said, "Oh, so when they ask you on Facebook if you're gay, they mean are you happy?" So I had to then explain and I said, "Well, no, I think they might be asking if you're homosexual," and he looked very worried and he turned and said to me, "Why do they want to know if I have sex at home?" But that's the lighter side.

The problem that we have identified in our submission is that the growth of autism has now reached a stage where the numbers are doubling every five years. This brings us to the point where in 20 years time there will be more autistic people than the whole of the present disabled community. This, if it is allowed to continue, will cripple state budgets and would cripple any insurance scheme that comes forward. So we have looked at this over a number of years and I will give you some figures to think of. Two years ago at the budget estimates here in Tasmania we got the opposition to ask questions on the number of autistic children in permanent care and so on and the number in group homes and rostered care situations, which we found 80 to 85 per cent had autism and other disabilities, amounted to a cost of $55 million in those two programs. That was precisely half the $110 million budget of the disability services in this state.

Last year we had the same questions asked and that 50 million is 64.5. Any increase in disability funding has gone directly into that area of long-term care. If we continue to do that it will eat up the state budget in the next 20 years and cripple the state. There is an enormous crisis in care for the intellectually disabled. We believe that would be followed - we don't have the capacity here, we're only a small organisation - to do the same type of figures for the other states, but we do know that the numbers are growing just as quickly in the other states as they are here. It is our opinion that if your commission recommends just extending an insurance scheme which continues the same situation at the moment with the same interventions, that the insurance scheme will never be able to meet the costs of looking after the children who are already in care and the ones that are coming because when you see that they're doubling every five years then those who are coming are far greater than the ones who are already in care.

We are suggesting that the present system of looking after the disabled with one care scheme, that is respite for the people who are looking after them by untrained carers, is not adequate at the present for what's coming in the future because what we're doing basically is training the children to be dependent and eventually when the carers can no longer keep going, they will end up in long-term care. That long-term care is enormously more costly than the cost of intervening right at the beginning. The cost of a proper early intervention scheme for these children can be as much as $1000 a week. But rostered care is much more than that, and all it's doing is babysitting.

What we're saying is that the human brain is far more malleable in its early years, at two years of age, than it is even by the time it's five or six when it comes to the school age. That is the area in which there is an opportunity to intervene if we can diagnose the children early, which there are schemes in art, we say and M-CHAT, but there are others - the Modified Childhood Autism Test, which are 95 per cent successful at 18 months and two years in picking up autism.

There are new schemes now - I saw one this week - that believes they can detect autism by a baby's saliva. Whether that is feasible or not, I don't know, but certainly if we can catch them at two years we have that three-year period that we can get them ready for school and then if the schools are trained to deal with them properly then we'll find the necessity for long-term care will decrease enormously. I'm not saying we can get everyone to live in the community but we can get them to be able to remain with their families.

40 per cent, it's estimated, of autistic children today never speak. There is no reason why that should exist, unless the child has dysarthria or something which is a physical disability which prevents the muscles in the throat working. But if there is no physical disability, every child with autism can be taught to speak. One of the easiest things we can do is teach them continence, yet in our schools in this state there are children still wearing nappies every day. This is a crime against these children. When we know how to fix it and we avoid doing it, we're creating the problem. The cruelty that I have seen in this area is a disgrace and a blight on our society.

The American situation - and let me say you probably will never believe this, but George Bush was a leader in looking after autistic children. In Texas, when he was the governor, it had the best services for autistic children in America. He brought in the No Child Left Behind legislation in America, followed by the idea for the school-age children. There's a lot we can learn from the American situation where if a child, when he goes to school, it is mandatory that they have an independent education plan, and it is mandatory that they check regularly to see that that plan is being met. Here we have them and they are fixed up at the beginning of the year, go in a drawer and they don't even have a scuff mark on them at the end of the year, because all we're doing is setting them aside with an aide, who is untrained in teaching them, to babysit. That babysitting is very, very costly.

Children in this state are breaking down regularly at school, becoming so violent that they're expelled from school and left, and the school then pays for them to have a babysitter in the home eight hours a day. They learn nothing yet when we do get one of these difficult children into a program and we start to have success, the attitude of those who are in the autism industry is we have to stop it because if there is precedents being formed, everyone will want this to be done for their children.

MS SCOTT: Roger, are you comfortable if I ask a question now?

MR LAW (ATAC): Yes.

MS SCOTT: What's the level of early intervention available in Tasmania at the moment? You clearly consider it to be inadequate and you've made the point that when it does occur that in fact there can be a perverse encouragement of people - - -

MR LAW (ATAC): The year before they go to school the state provides three hours of intervention per week. It's one hour with the parent, one hour dancing and playing, and one hour of tabletop work, which most parents after a few weeks say, "Well, this is bloody useless," and don't go. Privately, we have in Hobart a firm that will provide proper early intervention. It's costly. I think at the moment they have about 30 children. I know they do some outreach in Launceston, but outside of that there are not early intervention services available for these children. The early intervention services that are available don't use proper evidence based practices at all in the government.

Now, ISADD, which is the private firm, one of the largest in the world, they have an organisation in Europe, they are all over Asia, I think the person who is the leader of it, Jura Tender, she advises the government in Indonesia and so on. They have a very small group here in Hobart. Other than that, early intervention doesn't exist.

MS SCOTT: Effectively what you're proposing is what we now do for children regarding their hearing. Every child in Australia is now tested for hearing loss.

MR LAW (ATAC):   We would suggest that when they are given their early vaccination, first vaccination, they should also be tested for autism with the M-CHAT which would red flag those who did. In many ways we certainly do have a better health system than the Americans, and this could be utilised to give a proper diagnosis for these children, because it's not just their autism that's the problem, as we state in a submission, it's the comorbidities with autism. The ones who don't speak, there's no research that shows that it's their epilepsy which causes them not to speak. As they learn something they have continuous epileptic fits and lose it, so they never learn to speak.

We know that up to 30 to 40 per cent of autistic children also have epilepsy, yet it's not a regular, normal thing to test an autistic child for epilepsy. It's the greatest cause of premature death in children with autism.

MR KALISCH: Are children more likely to be identified with autism or with one of the other disabilities?

MR LAW (ATAC):   It depends; there's a lot of cerebral palsy et cetera that also have autism, because the problems have the same aetiology. The brain is the problem, the misfiring in the brain. What the ADA early intervention does, by breaking each thing down into its smallest components and teaching those components and building it up, it gradually rewires the brain so that they can move forward, and with constant testing you can find exactly what stage the child is at and work on it and build it up. Yes, it's a long process, it's very costly and we don't have the people trained in Australia to do it, but we do have a health system which could very quickly put all those people who are experts in the area of the comorbidities that we know of, they're all in the major hospitals. If, after they were screened and red-flagged in screening, they were sent for proper testing in the hospital, we can devise a health plan for them which includes looking after their comorbidities.

We would be able then to not be in the situation of training, teaching and teaching until you get a child to do something and then they lose it because of their epilepsy, because the epilepsy would be stabilised before you made the move.
50 per cent probably of autistic children also have ADHD and the research is now showing that those are the ones who are more violent. Let's not kid ourselves, some of them, you can't hide the fact that violence is endemic in our society and these two disabilities when combined are really showing that they're four times more likely than normal children to be violent. We can deal with that if we don't just treat them as autistic but we treat their autism and their ADHD.

MR KALISCH: Is it correct in my presumption that your hypothesis or your suggestion to us is that autism should be identified earlier and to a greater extent and then also dealt with in terms of successful early intervention strategies?

MR LAW (ATAC): Yes.

MR KALISCH: We have been talking a little bit about identification. The one thing that I presume you provide to us in a follow-up submission is about the success of those early intervention strategies. The American Paediatric Society has just recommended that all paediatricians in America use the Multiplied Childhood Autism Test at two years of age. Now, we don't need to reinvent the wheel, it's there. It's a very simple test. It could be implemented by the child health nurses, paediatricians and GPs. It only red flags, it gives you that indication, but it tells you then that those children should be properly diagnosed. Once that diagnosis is there the intervention can start. It's no good starting to intervene if you don't know what's wrong with the child.

MS SCOTT: I just want to check, John, do you have any questions, we're just towards the last few minutes with Roger?

MR WALSH: Patricia, I'm just interested in the intervention and, Roger, maybe if you could just tell me, suppose we did have an intervention which kicked in when the child was two years old or something, how long would that intervention be required and would that then be permanent - of the autism, the comorbidities?

MR LAW (ATAC): Obviously if you've got epilepsy it's a life-long thing, so that would have to continue, John.

MR WALSH: But it would be controlled by medication.

MR LAW (ATAC): Yes, but epilepsy is not just one disease, it can be the major seizure but you can have continuous small seizures all the time. It needs to be properly stabilised by an expert in that area. That child could have gastrointestinal troubles. GI troubles are endemic in autistic children. They're mainly not treated, or in some cases they're treated by special diets which people then think has cured the autism, but all it's done is fix up the gastro problem. Experts are in all our hospitals in that area and they should look at these children and set diets and so on for them. Then we can know that all we have to deal with are the two areas, the retardation, if there is retardation, and the autism, the socialisation and so on.

It's interesting, I had a glance of some of the stuff that come out of the meeting in America, and there they even got to the stage of developing a virtual person for the children to learn how to speak and how to say, "Good day," and properly socialise with, so that after they have learnt with the virtual person on the screen, they can then go into society and practise what they're learning. This would be an enormous advantage to our Asperger's kids.

MS SCOTT: I'm conscious we need to be careful with time. Roger, thank you very much for your submission to us and then coming along today. We look forward to a second submission from you, particularly picking up on the data that you were waiting on, and again thank you and we look forward to a further engagement with you.

MR LAW (ATAC): Right, thank you.

MS SCOTT: Our next witnesses are from Speak Out. If you could come forward and identify yourselves. Good morning. Could you please state your name and the organisation and the groups you're representing, please.

MS MALLETT (SO): Mary Mallett.

MS HUETT (SO): Judy Huett from Speak Out.

MR HUETT (SO): Peter Huett, Speak Out.

MR HARNWELL (SO): Derek Harnwell from Speak Out.

MS SCOTT: Thank you. Just for our recording, you might just need to speak a little louder, if that's all right. Thank you for that. Would you like to start off. We've got about 27 minutes or so. If you could just make an opening statement, if you wish, and then we just might give you a few questions as we go along.

MS HUETT (SO): I'd just like to tell everyone what Speak Out is all about. Speak Out is a small disability advocacy service which operates in Hobart, Launceston and Burnie. Speak Out is a membership organisation for people with intellectual disabilities.

MS SCOTT: Thank you.

MS MALLETT (SO): Judy is the members' president of Speak Out. Pete is the previous members' president and a current member. I'm the manager of the organisation and Derek is one of our disability advocates.

MS SCOTT: Thank you.

MS MALLETT (SO): First of all, we haven't written our submission yet and we'll be doing it closer to the deadline. What we've done so far is one consultation with a group of members with intellectual disability in Hobart. We have three regional self-advocacy groups that meet monthly. There's about 40 people in each of those groups. They're all people with intellectual disability. So we did one rushed consultation with the group in Hobart and I suppose I just want to make a comment about that. I think it will be difficult, it will be more difficult for you to hear the voice of the people with intellectual disability in this process and you may hear the voices of other groups of people with disability more than you do the voice of people with intellectual disability. It is very good that you've got the Easy English paper and that's what we used in the consultation.

One of the things is it has to be facilitated, it's got to be done properly and it takes time. We discussed it within the organisation, for us to prepare properly to come and do this presentation would have required a significant amount of time and input that we just didn't have in this short space of time, especially since Hobart is the very first hearing and probably some organisations down the track will have had more time. But to do it properly and to have more of the members involved today, what we would have needed to have done is to get a small group of people with intellectual disability together, go through those questions very methodically, give them time to think about the issues and develop their ideas, get the group back together two or three times, do some role play to show them what a hearing would be and about sitting and presenting.

As the current and past members' president, Peter and Judy, have had a reasonable amount of experience at talking to forums and presenting but many of the members wouldn't and even as informal as this is, they would find it very intimidating. So we will do more consultations and more of those smaller groups and I have spoken about the possibility of doing a video submission which we would like to do because I think we will be able to directly capture some views of people who won't be represented very well otherwise in this inquiry. One of the issues, I suppose, is that people with intellectual disability who are within the disability system are often very voiceless and very powerless.

MS HUETT (SO):   They're not always heard.

MS MALLETT (SO):   No, they're often not heard. They are completely dependent on the system, on the organisations who provide services, on the staff who provide support and sometimes that's reflected in their responses to the questions and we will just quickly run through some of these responses. But some of the ways people respond is reflected by their very limited experience within a very constrained life that they life within a system.

Another issue that I will just mention - and if we have time we'll come back to it - as I said, we haven't done our proper submission yet and there are so many issues and we don't have the economic expertise, we don't have the capacity to develop really very informed positions on what's going to be used to produce the income and whether it's a Medicare-type levy or some other system. I suppose we just see from the inside how the system affects people. But, I suppose, we do have a concern about the terms of reference that it's looking at people with profound and severe disabilities and we just wonder will there be two parallel systems, how on earth can that possibly work and with people who just are outside the profound and severe category be in an inferior system.

We don't have a view on it yet. We haven't come to grips with how it could work but we're concerned about it because we see, certainly as an advocacy service, many, many people who wouldn't be classified as profound and severely disabled but who live on the fringes, they're on the fringes of the disability system, they live on the fringes of society, they live very difficult lives, disadvantaged in every way.

MR HARNWELL (SO): Very marginalised in terms of the services available and the capacity of the system, I guess, to make sure that those services are adaptable to all circumstances and all form of disability, there are real issues, yes. Margaret Reynolds sitting over there has done a lot of work on the system here in Tasmania, not being able to recruit and retain people as staff within the sector and I think that's one of the big issues as well. People with disability do have a lot of ideas about what they want in their life, however, the system tends to work a little bit against them in their ability to be able to get that.

MS MALLETT (SO): I suppose because primarily here we are representing that voice of people with intellectual disability and so the "profound and severe" disturbs us somewhat because we see lots of people who wouldn't be classified as profound and severely disabled. They have a mild intellectual disability but, to be honest that sometimes makes things worse for them. Sometimes people who are entirely within the system at least are cared for and they have a system that protects them and provides them with support. If you're not disabled enough to be within that system, you're at the mercy of all of the people outside there who exploit people, bully them; people who live very difficult lives really.

In spite of all the nice words about how tolerant we are as a society, society is very intolerant of people who are different and people who look a bit different, dress a bit differently, don't communicate as well as others and just don't fit in. So if you stick to your terms of reference very strictly, those people will still be out there on the fringes living very sad, isolated lives.

MR HARNWELL (SO): I think some of the examples of people we work with, someone who has an intellectual disability plus mental health issues and is also providing and caring for a family member who also has some form of disability. Do they require less support or are less in need that someone who has a profound and severe disability? I guess what we're saying is we shouldn't be using the medical model maybe to decide who requires the most support when we can look at individual circumstances when people very much in need of a great deal of support.

MS SCOTT: Is there a phrase or a model in your mind - I know it's early days and I'm conscious of all the points you've made about timing and the need to consult and to facilitate discussions, so all of those points are well taken - that would incorporate the groups that you think are most deserving of being in the scheme because of their needs and requirements and how they're marginalised in society. You don't like "severe" or "profound" we've got that. Is there something that - - -

MR HARNWELL (SO): It's not that we don't like severe and profound, it's just ensuring that other people who don't come under that category - - -

MS SCOTT: I understand.

MR HARNWELL (SO): - - - are marginalised as well. So maybe in terms of individualised funding being available to enable people to be able to access the services they require, so people with severe and profound disability have a package that enables them to access what they need for their support services and also other people under different categories also have that funding available to them.

MS MALLETT (SO): Which is based on what they need. There's such limited resources and there are so many people who may be receiving some amount of support hours, but not the amount they actually need but they just have to make do with what they're getting.

MR WALSH: I have a question.

MS SCOTT: Yes, John.

MR WALSH: I'm interested in what that support might look like to a person with a mild or moderate intellectual disability to essentially go about their daily activities. What sort of support and what sort of support framework would be useful to put in place?

MR HARNWELL (SO): What I think is it's about giving people some choices. We talk very much about people with a disability having choices in their life, but those choices aren't realistic. People don't have a choice about where they live. If someone requires accommodation in a group home, a vacancy comes up and someone is basically offered the vacancy and that decision isn't based on whether the other people within the house are a suitable mix, whether transport is available in the local area, whether there are shops that have easy access. I think we just need probably more of a realistic vision of giving people choice. I don't think it's probably within our role to say this is exactly the structure that needs to be put in place. It's about listening to people with disability who say, "I want to have the option to live in a group home. I want it to be in an area that's close to transport and close to shops," or whatever. It all comes down to funding a lot of the time but people not being given the choices about something as important as where they live and who they live with.

MS MALLETT (SO): The other thing that I would say, that support that people need who have mild and moderate intellectual disability and who are living in the community, because often they should be able to access mainstream services. They shouldn't necessarily to always be using the specialist disability system but the responses of people who provide mainstream services are often very poor to people who look different and sound different and that would be the same with people with intellectual disability or people with mental health issues will often receive the same type of response which is not that they can't access, not that they will close the door on them but they just won't listen properly, won't spend the time to understand what the issues are and people will - - -

MS HUETT (SO): I'll agree there.

MS MALLETT (SO): So what happens is people remove themselves from the services. If it was as clear as they were being discriminated against and excluded then, you know, advocates would be able to jump and up and down and say, "Take them to the anti-discrimination tribunal," or whatever. But it's not quite like that. It's that people are received with this sort of indifferent attitude that just doesn't listen and find out what the person actually needs and make a bit of effort to fit the service to what the person needs and so that often what happens is people just withdraw and they tend to withdraw from society as well.

MR HARNWELL (SO): Also there's a big push for social inclusion at the moment and Judy and Peter are just about to head off in five days' time to Berlin, they've saved up and been doing barbecues and fundraising events to go to this big social inclusion conference in Berlin over the next couple of weeks. But how much time and energy is put into making sure that the idea of social inclusion is included in our schools, in our workplaces, things like that to ensure that people with a disability on the ground, in the community are being accepted within their communities. I'm not sure there's so much of a push, a lot is done at the political level within governments about social inclusion but how much money and time and energy is put into making sure the general community is including people with a disability within a community.

MS HUETT (SO): I actually have an example of that. I have a group of friends that have a disability that live in supported accommodation. They live independently. We went over to a football ground recently and we were over there playing football and we were just about on our way back and these people came over and started yelling that we were retarded. I don't see that as inclusion. I know that the people that they were talking to wanted to go home straightaway and shut themselves in. They didn't want to be out there where people are calling them names.

MS MALLETT (SO): This was two young guys in a ute who drove past this group of people who have a disability who were just out mucking around and said, "Eff off you retards," is what they yelled out the window of the ute to them. If people meet that kind of ignorance and abuse on a regular basis it makes them feel very unsafe in their communities and very disinclined for them to make the first move to go out and be part of their communities. That would be a very common experience.

MR HUETT (SO): There is one young lady who lives in that area and now she's too scared to go out, even in daytime because of that word "retarded" from the same people that live around that area.

MS MALLETT (SO): Unfortunately, people living with disadvantage who have many social issues because they can't afford to live where they choose to live, they are clustered in communities of disadvantaged, so some of those issues are more obvious in some of those communities than they might be if people were scattered more widely through the rest of the community.

MR HARNWELL (SO): I think there are numerous examples of people who are totally marginalised with their own communities and are being abused physically, verbally, attacked within their own communities.

MS MALLETT (SO): That's why we've got this kind of gut response to the limitation of the proposed scheme to profound and severe disability just because it will provide a solution for some people and it will do nothing to provide a better life for many other people.

MS SCOTT: So, Mary, if I understand your concept correctly, if the scheme is more inclusive than severe or profound, an assessment that took into account individualised needs, someone's support could be as simple as dropping in once a week or once a fortnight or being there to provide more or community support if someone had a bad experience, be able to provide some comfort, some encouragement to go out if somebody yells at you. In that sense for some people it could be very minimal support and for others quite substantial support with daily activities to assist them in their lives.

MS MALLETT (SO): Yes.

MS SCOTT: Thank you.

MR KALISCH: Is part of this directed toward the individual and, I suppose, the other dimension I was hearing from you is that it's also part of an education process of other service providers?

MS HUETT (SO): Definitely, yes.

MS MALLETT (SO): Yes, service providers and the wider community.

MR KALISCH: Yes.

MS MALLETT (SO): I supposed we're concerned, in Tasmania we're in the middle of a reform process and part of that reform is a push to push people with disability out of the specialist disability system and into the mainstream providers and we're hoping that will work better than the current examples we've got of where people are not met with good services and support.

MR KALISCH: So is that a sense that the mainstream service providers are more likely to enable people to essentially maintain contact through work, through employment, through other social activities?

MR HARNWELL (SO): We would say positive images that people with a disability - if people are working, if people are encouraged to dress well, to become part of their community and really involve themselves, there are some very positive images there, I guess. We certainly don't want there to be a push for people just accepting people with a disability because they've got a disability. There are a lot of programs that can be introduced to make sure that we're really emphasising the positives, sporting events, social clubs and things like that, there should be more involvement and more funding available.

MS MALLETT (SO): One of the limitations for people with disability being more involved in their communities is transport. There are cost issues anyway of belonging to clubs and associations and going to events but transport is probably without a doubt - - -

MR HARNWELL (SO): Especially in the north-west and the north probably more so than somewhere like Hobart, I guess, unless you live in the outer areas.

MS MALLETT (SO): As I said, this first initial consultation, certainly there are some comments in there about somebody who lives in a shared accommodation place whose staff will drop him off at the football at the weekend and he can't get picked up again and he is not able to get a bus or there isn't a bus and there are insufficient buses on Sundays in particular but at other times as well.

MS HUETT (SO): As a person with an intellectual disability I've got a full-time job. I work five days a week at a place called Ability Windscreens in Burnie and I'm assistant windscreen fitter. It's all good and it's freedom. I'm kind of on the pension but I still have to declare every fortnight but, the money that comes in, it's understandable.

MS MALLETT (SO): Pete's previous work history was quite a lot of time working within in what, in the very initial days would have been called a sheltered workshop, now they're disability enterprises and Pete has moved out of that system into open employment but many people don't. Really the system is badly designed and doesn't encourage or support people well to move out of the disability enterprises and into other types of employment.

MS SCOTT: One of our many areas of focus is participation and we've covered social participation and I can see the comments from your group meeting where people are talking about lack of opportunities to go out on weekends and so on but also participation in work. How limited are opportunities for open employment here in Tasmania?

MR HARNWELL (SO): I think the employment services actually provide quite a good service for that. They provide some support in the workplace for the first few weeks that might require going down to the workplace with the person who is getting a job. There are some quite positive things there. It is actually improving people's own consideration of their own capacity. A lot of people consider, "Supported workshops, that's the only option that's available to me," and making sure that people understand the choices they have and the options that are available, "Your options aren't only exclusively the supported workshop environment," and someone like Peter, you know, for someone to have met Peter and considered that he was a good candidate for supported employment was just doing him a total disservice because he does absolutely have the capacity to work full-time. We see a lot of that, okay, this person has a disability, they'll go into supported employment and earn $1.50 an hour whereas - that's why I think a lot of the advertising of the positives of someone with a disability, people with a disability take less days off, they're sick less, there are some really good statistics out there that show they can be incredibly good employees.

If we can get the community to have a greater understanding of the real positives of employing someone with a disability, that's where the change needs to come from, I guess, is promoting the positive.

MS MALLETT (SO): But we certainly see quite a lot our members who are underemployed certainly and absolutely not - their capacities are not being used in any way to the extent that they ought to be. They're not given the opportunities or, as Derek said, they don't themselves perhaps have the knowledge or awareness of what's out there and if they're not strongly supported by somebody and also given opportunities - if somebody is within a disability enterprise, for them to move out into open employment they might need the reassurance that, "I can go out and try something but I can come back and my job will here." That lack of security would be very frightening to someone who has been within a very secured, protected environment.

I just wanted to raise one issue that came up for a lot of discussion at consultation with the members which was the issue about holidays. There was a lot of discussion about the fact that people who - generally speaking these were people who live in group homes and who require support for staff. But for them to go on a holiday they have to pay for their staff to come too and one of Judy's friends was going to Melbourne but - - -

MS HUETT (SO): She was going to Melbourne for a holiday to meet up with her family but she ended up having to pay for her support worker as well and the accommodation for the support worker. So it didn't only take away the fact that she couldn't have done it herself but also the fact that she needed that support but it made her feel insecure in one way because she felt like she wasn't being independent.

MR HARNWELL (SO): Not trusted to be able to - - -

MS MALLETT (SO): Yes. We have a group of representative members from around the state who meet together regularly and the members group came down recently to take part in our strategic planning for our organisation and so one of the members from Launceston who was in a wheelchair and needs significant support but his organisation couldn't provide the van and a staff member that weekend so we organised for him to come down and we organised the support to be provided by a service in Hobart and I hadn't realised beforehand how important that was. He didn't want to go home.

MS HUETT (SO): He actually wanted to stay.

MR HUETT (SO): He wanted to stay another night.

MS MALLETT (SO): Yes, because this was the first time in I don't know how many years, many, many, 15 or 20 years probably that he had had one night away from the staff who he lives with and who provide his support all of the time. So just to have one night away from being within the confines of the organisation and the small number of staff who provide that support was really important to him and it a bit eye-opening for me really to realise just how significant it was. We don't have a solution for that issue about holidays, other than, you know, the creation of a recreation fund or something. It's an expensive issue for individuals.

MS SCOTT: Just drawing towards a close, I might take a chance to ask Peter, what made the biggest difference between getting into work you do now and what you were doing before? What were the best parts about it?

MR HUETT (SO): I left school in 83, that was a special school for people with disabilities. From that school I went into Summit, that was a sheltered workshop. I spent almost 15 years there. That kind of fell over, I lost everything. Then after that another job came up, that was fine. I left that one, stayed there a couple of years and then I found some work at Ability Windscreens in Burnie. I think the biggest difference I've found is the money that I'm making because at Summit I was making, I think it was $5 an hour, something like that. But now where I'm working it's $17 an hour and I get everything that the guys get. I get holiday pay, bonuses - which is two or three hundred dollars depending. Yes, it's just the money and I think the freedom of independence.

MR HARNWELL (SO): Just linking in there to the holiday thing, Pete's going to Berlin this week and I'm sure he wouldn't have had the ability to save up for that. They did a lot of fundraising but they've also saved a lot of money just from his employment. The opportunity that it's given him to do something instead of going to Bicheno or something like which is the tendency. He's heading off overseas, so what a great opportunity brought on by the fact that he is working in open employment.

MR HUETT (SO): Like the management at the place where I'm working, they're all fantastic. They know my history, they're just fantastic.

MR WALSH: Peter, could you just tell me, how did you get the job? Did you just apply for it?

MR HUETT (SO): No, Ability Employment, they're a special group for people with disabilities. They found me the job but my name was previous, before that. They did have some input into it.

MR WALSH: Thank you.

MS SCOTT: We're right on time, so thank you very much. All the best in the trip to Berlin.

MR HUETT (SO): Absolutely.

MS SCOTT: I appreciate the points about the time for consultation but it's also good to have this chance to see you here today. We look forward to further submissions. Thank you. We're now going to take a short break for morning and we'll start again promptly at 10 past 11.

MS SCOTT: We will now recommence our hearings with Advocacy Tasmania and we'd ask you to identify yourself for the transcript and maybe briefly explain a little bit about your organisation and then make an opening statement.

MR HARDAKER (AT): I'm Ken Hardaker, CEO of Advocacy Tasmania and with me is Robin Wilkinson who is vice-president of Advocacy Tasmania and David Owen, who is our policy officer. We haven't had time to put together a detailed written submission at this stage, but we certainly intend to submit over the next few weeks. So in considering today's hearing we thought we would focus just on a couple of issues that are particular importance to Advocacy Tasmania. We would like to comment around the role of advocacy because we think Advocacy has an important part to play in the current system and we believe should have an even more important role to play in the new system.

The second area we would like to talk about is around individualised funding which is an area that we had an interest in for a long time now and are aware that the commission is looking at this as an important part of the inquiry and we think that's a very positive and welcome thing so we would like to make some comments around that. I'll say a little bit about the organisation. I'll then hand over to Robin who is going to talk about her own personal experiences in this area and then I will hand on to David who will add a bit more depth to those two issues that I flagged.

Advocacy Tasmania has been around for 20-odd years now. We are an independent, community based advocacy organisation. Our advocacy programs are provided historically to people with disabilities and older people. In recent times we've taken on a new service to deal with people who use drug and alcohol services, so we've expanded the range of different target groups that we work with. The organisation is governed by a volunteer board of management so our board are representative of the different target groups where we work so they are either people with disabilities, people with mental health disorders, older people or carers. Because we are solely an advocacy service we believe that gives us an independence and a focus on working with the groups that we work with that enables us to concentrate very much on supporting people to exercise their rights as citizens and to help ensure that they are able to maximise the control that they have over their own lives. So we believe very strongly on the autonomy of the individual and providing support to people so that they can exercise that autonomy.

As I mentioned, we have a range of different advocacy programs, specifically disability and mental health works for people with disabilities and people with mental health disorders but all of our other advocacy program areas also have people with disabilities who use those services, so our home care program, our dementia advocacy program works with some people with early onset dementia in their 50s and 60s. Residential aged care program works with some younger people with disabilities in nursing homes, for example, and our new drug and alcohol advocacy service works with some people with acquired brain injury through alcohol-related abuse.

In any given year we provide individual advocacy to around about 1200 people and the majority of those are people with disabilities. So in the last year it's somewhere between eight and nine hundred of the 1200 were people with disabilities, the remaining being older people. The range of issues varies from - a lot of it is to do with accessing specialist disability services so a lot of the time of our advocacy is spent around issues to do with unmet need, people who can't access to services, who are desperate for services, people who are receiving services but are not able to get enough to support them adequately or have issues around the quality of those services. So the inquiry is something that we are very excited and welcome of because there is some hope that maybe some of this chronic problem of unmet need will be addressed.

We don't just look at issues to do with service delivery, it's anything to do with affecting people's basic quality of life and fundamental rights. So we deal with issues around abuse, housing is a common issue, criminal justice, employment, really the whole gamut of human experience where people's rights and quality of life is at stake. We think that probably gives us a reasonably unique perspective, certainly on Tasmania. We're a statewide service and we have offices on Hobart, Devonport and Launceston and so we feel we have a reasonably good understanding of the experiences of the people who use our services.

The way advocacy has tended to be viewed historically is one, in the disability sector, but probably more widely, as a reactive service or a reactive assistance. People have a problem, a complaint, a concern of some sort and they come to an advocacy service to help them resolve those complaints and concerns. We'd also like to think that a broader understanding of the role of advocacy can be encouraged and it's something we have been working on for the last few years and by that I mean a more proactive understanding of the role of advocacy.

So increasingly we are involved in providing individual advocates who support people through things like planning processes where they're thinking about their future and what sort of life they want to have; assessments of various sorts where often important decisions are being made and also substitute decision-making type processes. In all of those processes it's around maximising the ability of the individual to have a say and control the decision-making process. So increasingly we talk about our role as supported decision-making for people which we think is something that, if we are trying to strengthen the ability of the individual to have control and autonomy over their lives, then supported decision-making for people who are considered to have some impaired capacity, it becomes an important support.

As well as the individual advocacy that we provide, we also work at a service level. Sometimes that's through the individual cases that we take on provides insight into services as to what they're doing well or not doing well and that can lead to change. At other times it's in a more structured fashion so, for example, there's a large disability organisation in this state that provides residential services to people with intellectual disability and acquired brain injury where we provide independent advocates that support their resident communication processes. So they have resident groups that meet in different parts of the state, they come together as a collective to talk about their experiences of using the service, what's working for them, what's not working for them, independent advocates then help them to put that view forward to the management and the board of the organisation through resident representatives and that's an important way for that organisation to improve the quality and the responsiveness of what they do for the people who use their services.

That is a role that, in this instance, we take on because that organisation approached us to do that but most services like ourselves and Speak Out are often asked to do this sort of work but struggle to do it because it isn't resourced and we think that's another area that needs to be developed into the future. Lastly, before I hand on to Robin, the other comment I would make is around systems level advocacy. We are involved in trying to influence the way systems work in a whole range of ways, through different committees, through the current disability reform process in Tasmania involved in various different groups and advisory bodies and whenever we are taking that role we always try to be very clear about where we are drawing our knowledge from and it's from the experiences of the many hundreds of people who use our services each year. So we're able to communicate that into system change processes. That's probably I need to say, so I will hand over - - -

MS SCOTT: Just before you do, Ken, are you involved in advocacy in relation to assessment processes and eligibility processes at the moment?

MR HARDAKER (AT): Not directly, it's more about supporting individuals who are experiencing an assessment, so helping somebody prepare for an assessment, whether that's an ACAT assessment or some other sort of process; making sure they understand what they're being asked and able to really participate in the process less directly though. With the reform process there are a range of things that are happening so we do have the opportunity to comment on some of the proposed changes at the moment. There's a new system around Gateways being set up in Tasmania which is the way people will access services and there are different assessment processes associated with that which we've had a look at and been able to provide some brief comment on.

MS SCOTT: Okay.

MS WILKINSON (AT): Okay. Robin Wilkinson, and I've really cut this down to one example but there's lots of others that I would like to be able to put in later in the written submission. I am going to ask you as the Productivity Commission to imagine having very painful legs, going to see a specialist who says, "Your walking days are over, you should permanently use a wheelchair, as well as using morphine along with other psychotropic drugs to control the pain." This little scenario is not good for your emotional or mental health. However, armed - preferably with the left arm - a doctor's certificate when you are already very depressed, you start to find out how to obtain a suitable wheelchair. The community equipment scheme could provide it if you had $8000 readily available. But you're a person with a disability on an impoverished income and someone suggests that you should apply for a one-off personal individualised grant from Disability Services.

Disability Services accepts your application but says you're not a priority so the months tick by and you still have no guarantee of funding or wheelchair in sight. After about 12 months of lobbying very heavily, the funding finally comes through. Hallelujah, you think, maybe now you'll get your wheelchair. However, you have to be measured up for it and you have to choose what you think you might need but not actually see it or try it and the months continue on and on. After a total of about two and a half years you finally get your wheelchair. You have to pay an annual fee of $50 that arrives three weeks before Christmas and if you require maintenance on your chair, then that's another $50 every time you have it serviced, even though the machine might be faulty.

Approximately every two years you also require new batteries for your chair. The cost to you is $800 plus. Now, imagine again that you've been hospitalised for four weeks with an infected leg. You're supposed to have your leg raised as much as possible. Your current chair no longer meets requirements. A new chair will cost $20,000 plus. By this time as a person with a disability you are a little more savvy about the systems. The Seating Clinic will provide six and a half thousand and you apply for a one-off grant for 14,000 from Disability Services. But again you're not considered a priority as you do have your old chair, despite the fact it doesn't meet your needs.

After about another 18 months and much lobbying on your behalf, your funding finally comes through. Hallelujah again, you're ready to be measured et cetera but because of staff shortages and demand you have to wait a further 15 months or so to finally get your chair. Meanwhile you require further hospitalisation for your leg. A lovely occupational therapist at the hospital assesses you and your home environment. Her recommendations are: a new bed, commode chair, bathroom rails and a minor adjustment to your kitchen. All hospital equipment is finalised within six months but you still have no chair, at least not the new one.

By the time you obtain your chair most of the warranty time has elapsed. This is just one little aspect of my life and it sounds as though everything else is okay. I do wish that was so. Transitions in the lives of people with disabilities seem to be fraught with frustration. Imagine the stress just trying to obtain leg power. I use this as an example, I could have used personal care, I could have use a whole lot of other things and now that I've got the new chair, I'm not allowed to take that interstate because the airlines don't treat them very well so I have to take my faulty old one which will sometimes work, as it did for the Disability Summit, but sometimes doesn't work, as for a fortnight later when I was in Melbourne.

So I just wanted to use that as an example of some of the difficulties. Yes, I know a lot of it's on finance, but what all that does to you at an emotional and mental health level is really quite devastating and to be told you're not a priority is really hard stuff to handle. Yes, I do know people out there are worse off than I am but I hate the comparison because when you compare me with somebody else, the other person obviously has greater needs, their needs will be met first but where does that leave the individual? You're just hanging in space, it seems for ever. So I just use that as one example to hope you have some understanding, not only of the money issues but the emotional and mental health issues that accompany all of that.

MS SCOTT: Robin, just before we go on, how much of that delay would have been avoided if there was a system - maybe the chair is manufactured in America, we might not be manufacturing chairs here. But how much of that delay you encountered twice could have been avoided if there was an up-front assessment and funding provided for the individual's needs?

MS WILKINSON (AT): The waiting time would have been at least cut in half.

MS SCOTT: Thank you.

MS WILKINSON (AT): Absolutely.

MR OWEN (AT): I'd like to start by congratulating the commission on the issues paper that has been developed and published which we think is a remarkably comprehensive framing of the key issues. It has been challenging for us to work out how we respond to that issues paper. We made the rather depressing mistake - or I made the rather depressing mistake of counting the number of questions that were formally framed up in the paper. I got 232 separate paragraphs that were italicised and highlighted, some of which were composite questions. I think it would be closer to 200. We expect and anticipate that you'll be providing coherent and comprehensive answers to all of those questions. We on the other hand have the luxury of choosing only some of them.

Our triage process has led us to focus, as Ken indicated, on the advocacy process itself and on the arguments that we believe are very, very compelling for a major shift towards individualised funding: to move away from as well as to complement the existing block-funded approaches to service provision. We believe that the main thrust of a revised system should be about not just social inclusion, as our friends from Speak Out indicated, but citizenship. It should be essentially about a major shift that focuses on the decision-making capacity and opportunity for consumers - and when I say consumers, please understand that I am using that as shorthand for consumers and carers at all times.

We believe that the disability system in this state, and indeed elsewhere, is an underdeveloped one - not just an under-resourced one, but an underdeveloped one. By that we mean that it tends to focus on only two of the four major phases that any coherent service system needs to have. Those four phases, if you like, are an access one where a consumer learns about the service models that are available, the service providers that are available, and takes choices about how to negotiate that system; an engagement phase that Ken and Robin have talked about in terms of assessment and planning; the service delivery phase itself where the interventions are provided; and some kind of evaluation/follow-up phase that develops learning loops, feedback loops, for the system itself. Our assessment is that in this state in particular the disability system focuses only on the middle two. We see advocacy as an important part of changing that system to place a greater focus on consumer decision-making all the way through the four phases that we're talking about.

Our understanding is that a major shift in Australia's disability service system will be from the focus on substitute decision-making to supported decision-making. Ken and Robin talked before about our role in advocacy with substitute decision-making in the form of the various boards and tribunals that impact on orders, that impact in turn on consumers. We're here though talking about a block-funded service system that itself is a form of substitute decision-making where too many of the decisions that impact on consumers are taken by organisations and in fact imposed on consumers. We believe there's a significantly greater scope for consumers and carers to be directly involved in all aspects of decision-making but that they will require support.

We need to stress those learning loops, because without those learning loops service systems and individual service providers have very little opportunity to actually improve what they're doing. Again, our assessment is that they are largely absent at the moment with in the Tasmanian context but that a coherent and comprehensive system of advocacy is one way of dealing with that absence. Two basic models are being proposed in a sense within the issues paper for dealing with disabilities in Australia. One is a market model and one is what I would characterise as a kind of a membership model in terms of increasing the level of decision-making.

In the membership model basically consumers are encouraged to be more involved in decision-making at a service level and organisations are encouraged to provide the opportunities for consumers to be involved at a service level in decision-making. To do that, the consumer basically needs to have some allegiance to the organisation, a relationship with the organisation, very much like a membership form of obligation as well as entitlement. That's an important way of changing the system and we believe it has been underdeveloped in this state and elsewhere. The market model is very different in that sense: it suggests that consumers will be able to influence services by using their purchasing power. To do that, they basically have to be able to say to the service providers, "If you're not up to scratch we will walk. We will take that purchasing power and use it elsewhere."

It's very difficult to kind of reconcile those two models and to understand quite how the consumer will be able to take those choices as to whether they are going to use market power or engage directly in the operation, and perhaps governance, of the organisations that they so importantly need. Again, we believe that the advocacy process, including the kinds of services that we provide in our organisation, are one way of mediating what could be a very difficult choice. Advocacy provides an opportunity to support individuals irrespective of whether they are being a market actor - purchasing services and not purchasing others - or whether they're being a member - somebody who is trying to contribute to an organisation in a different way, to give more expression to that notion of citizenship within those organisations.

I won't go on too much further about that but I just want to make the point that - and it relates to earlier comments this morning about eligibility and about the need to be looking beyond the severe and profound component of eligibility. I want to stress this: that we're very aware that parallel to your important inquiry is another inquiry into Australia's aged care system, an equally ambitious inquiry by the way, that we will be also doing our best to contribute to by way of evidence and submissions. It's exceptionally important in the Tasmanian context that there be links between those inquiries. It's not possible to look at Tasmania's disability sector without seeing the intersection between the aged care issue and the more formal disability issue. We do that when we look at the network of services, the fabric of services.

Arguably, there are many, many more people receiving services relating to their disability, through HACC and through PEAK packages and EACH packages than there are through the state-administered disability service. But we also need to recognise that there is a major demographic change, transition, occurring in

Tasmania. We are ageing at a much faster rate than the other states. We know from existing evidence the importance of ageing in terms of the bringing forth of various disabilities, we know about the prevalence of disability through the life course. It's just not possible to try to imagine a future disability system, especially in a state like Tasmania, that doesn't take direct account of that demographic transition and seeks to make the linkages with the important changes that are being flagged in the aged care system as well.

MS SCOTT: Thank you. I'm just conscious of our time. John, would you like to start off with questions?

MR WALSH: I don't have any direct questions, Patricia, in his formal submission.

MS SCOTT: Just on the difference between the two models, as you were speaking I was trying to in my own mind see how a membership model and a consumer-type model could be related and I think it's not impossible to see how they could in the various stages in a process, even in the four steps in the process that you outlined - that they can be compatible. Certainly it's interesting to have that theoretical distinction drawn out, so that's useful. I would be particularly keen, I guess, when we see your submission for you to explore a little bit more this point about the difficulty in distinguishing requirements for ageing from the requirements of people and their carers who have a disability. So particularly I would encourage you to explore that further. We haven't had the time today, but that would be very interesting. Thank you very much - very useful.

MR OWEN (AT): Thank you.

MR KALISCH: And you don't need to answer all the questions.

MS SCOTT: Our next witness is Sue Hodgson. Welcome, Sue, to our inquiry. Could you just speak into the microphone, say your name and the organisations that you represent; or if you're just representing yourself, that's fine.

MS HODGSON (YPINH): My name is Sue Hodgson. I'm here partly representing the Young People in Nursing Homes National Alliance, with which I'm involved. I also have a personal journey which has led me into being involved in other issues, and I currently chair the Minister's Disability Advisory Committee in Tasmania.

MS SCOTT: Would you like to just make a short statement on your particular perspective on this inquiry and what you'd like to see come out of it, if we could start there.

MS HODGSON (YPINH): I guess if I just briefly give a bit of a personal journey. My daughter received a severe brain injury in Christmas 1985, which was my first introduction to disability and the issues surrounding it, and over that time she has been left with very severe disabilities, and she has lived at home with us for the past 23 years. Eight and a half years ago she married a slightly younger man who also has a brain injury; and that has brought another perspective into our lives, I guess.

When we started this journey my daughter was one of five young people in the Royal Hobart Hospital with acquired brain injuries who had no compensation and had nowhere to go. One of the young men had been in the hospital for 18 months. So one of the other mothers and I co-founded Headway and when we took our children home, our young adults home, we worked in a voluntary capacity for quite a few years until we managed to get some money, and Headway now runs a support service separately.

After we came home and discovered the difficulties of actually accessing rehabilitation - and a little bit further down the track Chris Cuff came and did a report for us, after we took a delegation to Robin Gray, and following the Cuff Report the Motor Accidents Insurance Board became very involved, under their then CEO, Laurie Caley, and we had for a short period of time a partnership between the state government and the Motor Accidents Insurance Board, which was working extremely well, in terms of moving forward and allowing people who were non-compensable to be involved with some of the advantages of the people who were receiving compensation.

I suppose that opened my eyes to the two-tiered system that was going on and the difficulties particularly in a state of this size. I know the previous speaker mentioned the demographic changes that are occurring, but we also obviously have a geographic situation which is different from the main states, in that we are an island state, we are very small and we have a scattered population. So this meant that we needed to get a critical mass in order to be employing trained people that could work with brain injury, to be able to get the equipment that we needed. We didn't have that critical mass while we were working in separation.

The Motor Accidents Insurance Board put up the capital funds for accommodation, things like this, access to the rehab centre here; and the state government put in the money for personal care needs and the other issues. Unfortunately - I think partly due to parochialism, but other issues too - the state-of-the-art inpatient unit that was built for early rehab lasted for four years; and over that four years, instead of being dedicated to brain injury and spinal cord injury - it was a 24-bed unit for both - it became opened up for people my age with hip displacements and things like that, and consequently it wound down pretty well as being a state-of-the-art centre for brain injury.

So over that time we thought we were moving ahead and we were going to move into the next stage, in terms of accommodation, but what actually happened was that that premises is now owned by the Catholic Education, used as offices, which is tragic in many ways but I guess indicative of the sort of things have bothered me over the years. We still have a two-tiered system. Robin was outlining before her problems with her wheelchair. We could have brought another member of our Minister's Disability Advisory Committee, who has compensation, who has been able to get all the equipment that she needs. It doesn't solve her problems, obviously, but it means that she can live life to a much easier degree and a much fuller degree than someone like Robin can.

After Headway had some money and my daughter could go there and free me up for a few hours, I was employed through the brain injury program, which introduced me to a range of other people and also introduced me to Advocacy Tas, where I am now a board member, and to Young People in Nursing Homes National Alliance. I think you're probably aware the alliance has worked, with a lot of lobbying, in an attempt to stop young people being inappropriately placed in nursing homes.

The COAG initiative, Young People in Residential Aged Care, has assisted to an extent but it has been fraught with problems. For example, a particular issue here is that if a lot of money is spent on a magnificent building but it's sited incorrectly and you move six young people out of a nursing home into this one house again you're in danger of starting another mini institution. As Robin alluded to, we are going through a reform process here, of which I'm sure you're aware, in theory it's going to be a very good system, but the sorts of issues that Ken raised, and David I think, in terms of people being able to speak for themselves, is of concern.

The standards, the quality improvement process that's being worked through, still almost pay lip service to the actual consumer, because, unless we have got some independent means of assessing what is going on, evaluating services - you know, if a service, be it an accommodation service or a day program or whatever, if it gets a sheet of paper that asks the people present if they're happy and ticks a few boxes - it's not really getting the answers that we need to get.

MS SCOTT: On this sort of governance and auditing, and it borders on to advocacy, Sue, is there a model either in Tasmania or Australia or internationally that you know of that we should look at that you think provides a better means to ensure that service standards or consumer needs are being addressed appropriately?

MS HODGSON (YPINH): No, I'm not currently aware of any particular system. I do know that in an earlier project, the LIP program, Living Independently Project, that ran a couple of years ago, an advocacy program was built into that and that worked extremely well. I think it's a case of ensuring that there is advocacy on the ground to assist people and that there is an independent auditor of some sort. I know that the department has been transferring the services that it ran to the non-government sector, which frees it up, in a way, to be the funding body and the evaluating body, but it's still a bit problematic determining whether that's totally independent.

MS SCOTT: Thank you.

MS HODGSON (YPINH): I would also like to say when we're talking about people having a say, and I think David mentioned the membership market, from a membership point of view, with another hat on, due to my daughter's situation, 15 years ago we formed another group called HOPES to look at alternative forms of accommodation for people with, particularly, acquired brain injury and neurological conditions, and, 15 years and four submissions later, I guess largely due to the current national building stimulus package we actually are now realising our dreams, in a slightly comprised way, but this process, we have 14 units now, 12 of which will be used for individuals' living and the other two for a common house and a transition-respite house. Our model is a cooperative model where we are actually - and it's very new so we are hoping it will work, but the residents themselves, with an advocate of their choosing, be it family member or a friend or whoever, form a cooperative to determine their own lifestyle and their day-to-day management. Our first seven residents moved in in the last week so it's early days to know if it's going to work.

MR KALISCH: Do you want to explain a little bit more how that housing is situated, what sort of choices they have come up with?

MS HODGSON (YPINH): Yes. When we started HOPES many years ago we got together a group of people who had mostly acquired brain injury, some people with MS and a couple of people with cerebral palsy, and at that time Huntington's disease too which became a bit problematic because of its fast, progressive nature. We sat down with them and said, "Now, if you had - you know, if you could dream the dream what would your world look like?" I guess particularly for people who had acquired their disability they had a memory of their past lives and so they were very keen to be as independent as possible. Some of them, I guess, lacked insight into what their difficulties were but in most cases they know that they wanted help, they needed support - some quite a lot of support, but they wanted an individual space.

So out of that came this model, I suppose, of a cluster of units but with a common house. The intention at that stage was that the common house transition-respite would be one unit and the units themselves would - some of them could be double units so family could live on the other side initially, or whatever. What actually has now happened is we were successful with the building stimulus package and we thought we were building in conjunction with the Housing Innovations Unit. They were building 20 units, 12 of which would be for HOPES on land, very suitable land, and we had 18 months to plan it and we planned to start with the residents building up what they wanted. What actually happened was that title to this land was becoming difficult and was going to stretch the situation out too far and so were offered, with a 24-hour decision period, another site - a very suitable site but a site where the builder was ready to pour the foundations for 14 units not designed for wheelchairs.

So our comprises started, and that was only in November of last year. Suddenly the units are completed and we've had a very steep learning curve, I suppose, to work through in that time. So most of the units have one individual - they're all two-bedroom units and most have one individual living in them. My son-in-law moved in at the weekend and my daughter is moving in tonight - fraught with difficulty - and then we've got five units that we're still working through applications because from our point of view the most important thing is that people are compatible and that they can contribute. But, as you can imagine, because of the number of people wanting accommodation we've had endless people hoping to join in - and it's just one model, it doesn't work for everybody. We're hoping it will work for us. The choices up until then have been group homes predominantly for people with intellectual disability and with very little emphasis on compatibility, which is a problem.

MR WALSH: Sue, can I ask if that model, which is, I guess, a sort of a cluster model, I suppose - is there a timed person on site all 24 hours?

MS HODGSON (YPINH): What we've managed to do, John, Disability Services have been very supportive and they have given us some funds for a sleepover seven nights a week and a small amount of on-site shared support. The other advantage, I suppose, we hope, of what we're doing is that the people on site have - some people have independent individual support packages and we're sharing those around. For instance, my daughter and another young man both use the same service provider and we have been able to link some of their support in and use them as sleepovers too. I think that's another - what we perceive or perceived as the value of our model is that we can share resources and that it should be cost effective, we hope. So there won't be 24-hour care, and we have said to people when they come in they need to bring their own support. But having said that, we will have a sleepover every night for people to contact and part of that time - there will be an hour in the morning and an hour in the evening when that shared support will go round and see what people's needs are. We are also utilising friends and family to do things like help with the garden and to create a community, I suppose.

MR WALSH: I think, Patricia, it would be useful to have a submission on that model, maybe the economics of it, or the way in which it was built up.

MS HODGSON (YPINH): We're happy to do that. We haven't had time to put the submission together at the moment and our cost analysis has changed over the last few months, but we're getting our act together now and we would be more than happy to put that in.

MS SCOTT: It would be good.

MR KALISCH: The interest for us, this is actually a real model. I mean, you've actually got people living in there, you've had the experience of developing it and seeing some of the difficulties that you've had to face in sort of planning or other dimensions.

MS HODGSON (YPINH): Yes, we certainly have. I wasn't grey to start with.

MS SCOTT: I'm also interested in your concern about many institutions as well. Clearly, that has been very conscious in your mind. Maybe when you have your submission you might particularly address that because we have heard, even at this early stage, very diverse views about the practicality of complete choice and the feasibility of it versus the desire not to head towards institutions again. So that's why, I guess, you can understand we're interested in.

MS HODGSON (YPINH): If I've got time I can just quickly anecdotally tell you a couple of things about the house that happened here. I guess from the minister's disability advisory committee point of view we heard what was going on in terms of the design after it was actually on paper, and asked to have a look at it. Initial concerns were that it's a four-bedroom house with two units at the back. Anyone living in the back units had to come in through five sets of doors to get to the units, which we thought was a bit strange, and it was virtually impossible to go down the sides in a wheelchair because they had these beautiful gardens. When we asked about this we were told that, "Well, one of the people transferring from the nursing home is likely to be in bed 22 hours out of the 24 and so they need a nice view."

So the first thought was, "Is there much point in transferring from one bed to another bed?" and if you can't get out in the garden - you know. So that was the first concern, and when we tried to make some changes they did accept some things but in a very limited fashion. To see the house, it is very large, which is good for wheelchairs to have access, but it also makes it very difficult to become homely. The six people that have moved in all moved in in the one week, which was an absolute nightmare for the people running the house but also very difficult for the people coming in, and when I asked about the two units at the back which were originally designed for people with a high level of independence, I was told that unfortunately the choice was, which of these six people can press a button for help. Only two of them could, and they're the two living in the units.

The position that it's sited on - and I think this has probably happened on several occasions for group homes too - is a piece of land that was owned by the government, so it's a useful piece to put the house on, but those people going out of that house will need to be transported by bus to get down into any sort of a community. So you then ask yourself, "What are they gaining from where they were to here?" They may gain a lot but it will be very much up to the staff and people coming in. It's not the sort of place where a family member or friend can come and take them around the corner for a coffee. You know, it just doesn't work. So those are the sort of anecdotal concerns.

MS SCOTT: It's the site, it's about placement, it's about design, about planning and funding and compatibility and outlook aspect.

MS HODGSON (YPINH): All those things, yes.

MR KALISCH: Co-location with services, with employment, with other things.

MS HODGSON (YPINH): Yes. I guess, just as an aside to that, I think part of the problem with those - and similarly with our situation now, when there's government money coming through it's like this is a project, it's a two-year or five-year project or whatever it is, you need to spend your money by that time. Firstly, there's no guarantees about what happens after that, which is a major concern, but the other is that you are doing things in a way that perhaps - you're trying to stick to a deadline. Whereas we certainly wouldn't want to see things dragging on, but I think you can speed things up to the detriment of the funding program.

MS SCOTT: Thank you. John, do you have any questions?

MR WALSH: No, thank you.

MS SCOTT: Is there anything more you would like to say, Sue?

MS HODGSON (YPINH): No, I think that's fine. We will genuinely try and get a submission to you.

MS SCOTT: In this case, as I've said with the others, if you concentrate on your strengths, I guess, in answering questions and in particular we would very much appreciate any information you could give us about this smaller cluster model and what you think that would offer.

MS HODGSON (YPINH): I would be happy to, yes. Hopefully, we'll get it in before it's all fallen apart.

MS SCOTT: Thank you very much.

MR KALISCH: Thank you.

MS SCOTT: We're just a little ahead of schedule which is not necessarily a bad thing and our next witness is Ann MacArthur. Just while Ann is getting her papers ready, can I just check if there is anyone who would like to avail themselves of the opportunity to make a brief comment at the end of this that's in the open area? No-one? Okay.

MS SCOTT: Could you just identify yourself.

MS MacARTHUR: Yes, my name is Ann MacArthur and I'm 47 years of age and I've had a lifelong problem with being able to read, write and understand symbolic language which you might think is not particularly much of a problem. I don't actually have a hearing impairment or a visual impairment and I don't have a fine motor skills problem and what that comes under is something called dyslexia. If you have literacy difficulties you have a big problem being able to get particular types of work or being able to be retrained. In my case, in 1995 I was a cleaner, I ended up injuring my shoulder and I ended up in the workers comp system but because of what I've got it was very difficult to get back into work and I'm still working as a cleaner but I can't do it full-time. I've tried to go to university, I've tried doing TAFE courses, it keeps coming back to haunt me.

It also raises the issue of just what should constitute a debilitating condition or a disability because I've been told in no uncertain terms by people who deal with things like autism or visual impairment and hearing impairment "it's not a real one" and it's sort of like, "Well, who's to decide what's real or what's not." I can actually read or write but if information gets too complex, like reading text books is amazingly difficult. So if what you have to do all day is actually access written information and physically write words, then you're pretty stuffed really. Considering we've got such a huge percentage of the population with general literacy problems, we're a really good reflection of how people with literacy problems are treated.

So I just wanted to go through some things - adult literacy in Australia, there are something along the lines of 47 per cent of the adult population have difficulty reading and writing, that's between the ages of 15 and 74.

MS SCOTT: What was that figure again?

MS MacARTHUR: 47 per cent of the population.

MS SCOTT: 47 per cent.

MS MacARTHUR: That's between 15 and 74. That's from something called the ALLS survey done by the Australian Bureau of Statistics. People with what I've got, there would be a disproportionately high number of people with dyslexia within that group. It is estimated that between 8 to 10 per cent of a population has dyslexia to some degree or another. I'm actually at the severe end. It usually falls between mild to severe and in my case mine fluctuates between moderate to severe, depending on what I'm doing. What it is is actually a neurological difference in how the brain processes written information. It affects reading, writing, spelling, grammar and, in a lot of cases, maths but that's due to the language of it and interpreting symbolic language which a lot of maths and sciences is symbolic language.

It's known that there is something called a reading network, there are three distinct areas that are within it. In our case two very prominent areas actually work at a reduced rate, that's actually been proved as real. The problem is in Australia at the moment virtually all states and territories don't accept dyslexia as actually being - they define it as something called a learning difficulty which is incredibly vague. It's usually put under that term as it can be any social, cultural, intellectual or any reason why somebody has a problem learning. It should actually be put under something called learning disabilities which would include dysgraphia which is a problem with fine motor skills in writing. They have got one which is called dyscalculia which is maths which isn't quite the same as the problem I've got and basically they don't do this here in Tasmania. It's not acknowledged officially in the Disabilities Discrimination Act. The Education Department acknowledges it's real but they actually won't do anything about it.

MS SCOTT: If 47 per cent of the population have literacy problems, do you have any figures on what proportion have moderate or severe dyslexia?

MS MacARTHUR: About 2.1 million people, that's 10 per cent. Out of that 47 per cent I have no idea because they never asked the question because it wasn't included, "Do you have a learning disability such as dyslexia?" They were only testing general literacy skills. They never bothered to ask, "Have you got a problem?" which would have been quite helpful to find out. As I said, it's not actually understood or taken that seriously. The only people who take it seriously are those that have to deal with it as in psychologists or people who come across it. Outside of that it's a bit hard.

Defining it is at times difficult. Unfortunately, using the learning disabilities - I've written here it's basically - learning difficulties are so vague as to be useless. It means the educational authorities do not have to take responsibility for groups of students with specific needs and make sure their needs are met and make sure teachers are aware of how to deal with it. But that's not only within the school system, it's also out in adult literacy outside the school system. But what is happening in the school system is a very good reflection of what's actually occurring outside of it as well.

The Tasmanian Education Department for their submission into students with disabilities said, "We accept that any definition is a continuum of special education need. Where do you draw a line to say this group we will fund? We will always to a certain degree depend on funding and other factors. There will never be a definitive definition of disability." So they sort of wiggle out of it by saying it's too hard to actually state there is a specific group of people with a specific need, and yet within disability you have to define it to actually have a target group to give money to and for research and all sorts of things. You just don't give it away and go, "We hope you can get help."

The disability inquiry went on to state, "Educational authorities argue that special education policy provides for all students with special needs. Various literacy and numeracy programs are used to support these students with special needs who might not meet the criteria of specific disability funding but nevertheless have a learning difficulty." That's actually not quite true. In relation to disability funding it usually goes to the traditional disabilities - hearing impairment, visual impairment, mobility, those with profound problems that are quite - they're basically so obvious that they can't deny their existence, so they'd be cutting their own throats if they said they didn't.

It needs to be defined properly. By them saying that you can actually define it - the British Dyslexia Association defines dyslexia - "is a specific learning difficulty" - they use the term "difficulty" in the UK - "which mainly affects the development of literacy and language skills. It is likely to be present at birth and life-long in its effects. It is characterised by difficulties with phonological processing, rapid naming, working memory, processing speed and other automatic developmental skills that may not match up to the individual's other cognitive abilities." It actually is more than just reading. The BDA has changed their definition. When you say dyslexia in the UK they usually mean it also includes not just reading but short-term memory, organisation, sequencing, auditory and visual perception - which is related to using written language, alphabetic, numeric and musical notation. So it includes written language, it doesn't just mean reading.

MR KALISCH: So, Ann, are there particular services that are useful or that you would be looking to see further developed?

MS MacARTHUR: As far as I'm concerned any of the groups in Australia at the moment who supposedly are looking after our best interests haven't been doing their job properly. I think what needs to be done is a long, hard look at the groups that are out there. ALDA, which is Australian Learning Disabilities Association, they tend to concentrate on very early acquisition stages of reading written language but I'm beyond that, and their definition doesn't take into account the fact that I've got two types of dyslexia - phonological as well as something called visual. Their new definition they've just adopted, which I'm going into, only incorporates the sound-based part of written language, not the visual part, and I don't understand how they can miss that, because effectively their new definition states that technically I don't exist because I don't fit two of their categories, which I'll go into later. I'll explain that later. Yes, it's interesting.

I've got here, Identification of Dyslexics in the Education System and as an Adult. You have to go to a psychologist to have very specific testing. They use an IQ test to look at particular ways the brain processes information - I've had some very interesting interpretations of those results - and then they're supposed to go on and give more specialised testing, something called the Woodcock Johnson Reading Battery which actually looks at word attack skills, sound blending, phonological awareness and, in my case, mine are actually less than someone from grade 5. So they're key indicators that your brain isn't actually doing what it's supposed to do when you see written language. So somehow I managed to learn to read and write.

The problem is I actually ended up going to nine psychologists, in and out of the education system, and only one actually knew what they were doing. So the idea of where do you go, it's very hard to get a second opinion from a psychologist because you've actually got to pay a lot of money to have the testing done. It can be up to $1000, so most people can't afford it. The only reason I could do it was because I got a payout from my shoulder injury and I was able to start asking questions and finding out about it. There is actually no nationally accepted guidelines for testing in relation to us and/or developing appropriate strategies. There isn't a nationally accepted accreditation of psychologists, which needs to be done, because I have been told some very interesting things by psychologists, and if you're going to cough up a lot of money you'd hope that these people know what they're doing.

There's a big problem in the education system, which most people would have been hearing about - the reintroduction of phonics back into the English curriculum. There's actually a reason for it. Over the past 30-odd years there has been a bit of an ideological tug-of-war going on and they've been using something called whole language theory for the teaching of literacy - and for people with underlying neurological conditions you need direct, explicit instruction to actually match sounds to symbols to make sense of what you're doing. Unfortunately, whole language sort of is the end process once you become an accomplished reader and it sort of shows you whole words and sometimes if you're shown whole words you actually can't work out what the hell is put in front of you. So that has had a major, major effect on people with dyslexia in the past 30-odd years.

On the other side of it you've got the - it was also matched to something called constructivist theory. It was more the constructivist part that was the real problem because it actually had teachers using very indirect teaching methods that were not actually explicit enough. So a lot of people with dyslexia, whether mild to severe, would have actually been coming out with literacy problems. But they'll deny that; they don't want to know. With whole language instruction there was no direct instruction in linking sounds to symbols. They used whole words or whole sentences and you were supposed to gain meaning from what you were saying, but as I've tried to explain to people, if you don't know what the word is you can't actually gain meaning from it.

There was no correction of words if not correctly identified while reading or writing. They would allow people to guess or substitute words, so they wouldn't know if the child - or adult - was actually having a problem, not understanding what that sequence of letters was.

MS SCOTT: Sue, we're just starting to draw now to the end of your time. Would you be comfortable if we asked you some questions that might draw out some of the things that I think you're very keen for us to hear, or do you want to go straight to your conclusions? I mean, it's up to you.

MS MacARTHUR: I just wanted to raise teacher training. In this country the push back to phonics helps us. It's like a compensatory strategy, but it's not everything. It doesn't actually include helping us with sequencing or memory problems, especially in relation to maths and sciences. In the UK all undergraduate teachers are trained to understand dyslexia and other learning disabilities. I actually raised this issue at the forum that was held last year in dyslexia, but, unfortunately, they wouldn't listen to what I said. The bottom line is we need to change attitudes for hidden disabilities as well as allowing people to come forward and say that they have got a literacy problem without them being ridiculed or trivialised, because you risk losing your job. Most people assume dyslexia is like reversing letters or using tinted lenses or stuff like that. It's just not true; it's much more complicated than that. The organisations that have been set up in this country at the moment aren't actually explaining that to people and they're focusing too much on early literacy and there's not like a big person's version of it.

MS SCOTT: How did you acquire your shoulder injury because of your dyslexia?

MS MacARTHUR: No, it wasn't because of dyslexia; it was my working as a cleaner.

MS SCOTT: I see. So there wasn't a link between the two?

MS MacARTHUR: No.

MS SCOTT: I'm sorry, I misunderstood that.

MS MacARTHUR: Last year Bill Shorten got a group of people, myself and a whole heap of others, together to come up with an action plan for dyslexia.; unfortunately, it got hijacked by the professionals. A big problem with dyslexia in this country is that virtually all the information is actually owned and controlled by professionals, like psychologists, speech pathologists, cognitive neuro-scientists.

They have got it pretty wrong what we are, and there's not much I can do about it. I don't feel that people with dyslexia have a voice, because highly literate, highly educated people are determining what we are, they're not listening to what we say to them, unlike what happens in the UK. Basically, I want it taken seriously and what we have to say and what happens to us should be taken just as seriously as what a person with a university degree has to say, which is not happening.

MS SCOTT: Thank you. John, are there any questions you'd like to put to Ann?

MR WALSH: Yes. Thank you for your evidence. I'm just wondering, you mentioned the UK a few times as somewhere where people with dyslexia are given a bigger voice than they are in Australia, do you have any contacts or research material from the UK that we could have a look at?

MS MacARTHUR: Yes, I've got some information that you can look at. I'm putting it in to my written submission, when I can actually finish it, because it's very complicated. Yes, I do, I've got a lot of information from the British Dyslexia Association and Dyslexia Scotland, they're very good.

MR KALISCH: So is that available on a web site?

MS MacARTHUR: Yes, it is.

MR KALISCH: To some extent, even if we could get access to that web site while you're still writing that submission, or if you could send that to us at an earlier stage, that would be useful.

MS MacARTHUR: I can give some information to Hudan - - -

MR KALISCH: To Hudan. Yes.

MS SCOTT: Yes, that's good.

MS MacARTHUR: - - - and I can give you a copy of the Dyslexia Working Party's national agenda, which looks wonderful, but, from where I'm sitting, it's a catastrophe, and I can't get any of these people to listen what I'm saying.

MS SCOTT: I guess what we're looking for in your submission is what you think has to be provided to address the problem. You've mentioned teacher education and phonics and so on. But, you know, the fashion has come back to phonics.

MS MacARTHUR: I agree with you on that.

MS SCOTT: What do you want to happen - - -

MS MACARTHUR: I wanted to start up a dyslexia organisation similar to Beyond Blue, because it's actually very much orientated to people with depression, and all sides get in to talk. The professionals can come in and have their bit. The people with depression can say what they think. There isn't an organisation in Australia just for dyslexia, they're actually either learning disabilities or SpLD, as in specific learning difficulties. We need one organisation with the word "dyslexia" in it.

MS SCOTT: All right. Thank you very much for your time today. We look forward to getting your submission. I did ask before if there was anyone else who wanted to speak, and I think the answer was there was no-one. Still no-one? All right, well, I think I will then adjourn these proceedings. Our public hearings will resume tomorrow in Melbourne. We thank people for participating today, for providing submissions, and look forward to further submissions from you. So thank you very much and thank you for attending.

AT 12.25 PM THE INQUIRY WAS ADJOURNED UNTIL
TUESDAY, 8 JUNE 2010