SPARK AND CANNON

Telephone:

Adelaide	(08) 8212 3699
Hobart	(03) 6224 2499
Melbourne	(03) 9670 6989
Perth	(08) 9325 4577
Sydney	(02) 9211 4077

TRANSCRIPT OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY DISCRIMINATION ACT

MRS H. OWENS, Presiding Commissioner
MS C. McKENZIE, Commissioner

TRANSCRIPT OF PROCEEDINGS

AT ADELAIDE ON FRIDAY, 4 JULY 2003, AT 9.13 AM

Continued from 3/7/03

MRS OWENS: Good morning and welcome to the public hearing for the Productivity Commission inquiry into the Disability Discrimination Act 1992, which we will refer to as the DDA. My name is Helen Owens and I am presiding commissioner on this inquiry and on my left is my associate commissioner, Cate McKenzie. The hearing will have breaks for morning tea and lunch and, at the end of the day, there is afternoon tea. We will need to stick fairly closely to the timetable. You are welcome to take a break if you need to and re-enter at any time.

On 5 February this year the government asked the commission to review the DDA and the Disability Discrimination Regulations 1996. The terms of reference for the inquiry ask us to examine the social impacts of the DDA on people with disabilities and on the community as a whole. Among other things the commission is required to assess the costs and benefits of the DDA and its effectiveness in achieving its objectives. We have already talked informally to a range of organisations and individuals with an interest in these issues, and submissions have been coming into the inquiry following the release of the issues paper in March. We are grateful for the valuable opinions and contributions we have received to date.

The purpose of this hearing is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. We have already held hearings in Darwin, Brisbane, Hobart, Canberra, Perth and, yesterday, here in Adelaide, and following the hearing today there will be hearings in Sydney and Melbourne. We will then prepare a draft report for public comment, which we will release in October this year, and there will be another round of hearings after interested parties have had time to look at the draft report.

We like to conduct all the hearings in a reasonably informal manner, but I will remind participants that a full transcript is being taken. For this reason and to assist people using the hearing loop, comments from the floor cannot be taken because they won't be heard by the microphones. If anyone in the audience does want to speak I will be allowing some time at the end of proceedings today for you to do so. 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 issues raised in other submissions. The transcript will be available on the commission's web site in Word format, following the hearing. I now invite our first participant today, the Cora Barclay Centre, to participate, and I would like you each to give your name and your position, or the context in which you are appearing today.

MS HARRIS: My name is Claire Harris and I chair the advocacy committee at the Cora Barclay Centre.

DR DUNCAN: My name is Jill Duncan and I am the director of the Cora Barclay Centre.

MS HIGGS: My name is Naomi Higgs. I'm a parent of a child with a cochlear implant and I am also president of Parents of the Hearing Impaired of South Australia, which is a volunteer body run by parents, providing support and advocacy for children with a hearing loss, and their families.

MRS OWENS: Thank you, and thank you very much for the submission, which both Cate and I have read. I thought it was a nice balance of views and background material, but I know that you each want to make a few introductory comments for us, so please go ahead. Jill, are you going to start us off?

DR DUNCAN: Yes, thank you. I just wanted to contextualise South Australia in terms of intervention for hearing impaired children. The Cora Barclay Centre is a non-government, charitable organisation, and our methodology is to assist children in the development of spoken language through the use of their residual hearing. In South Australia, after a child has been diagnosed with a hearing loss, they see a woman - a person who happens to be a woman - who is an educational psychologist and she helps them in the decision-making process in terms of where their child should receive intervention and what type of intervention would be appropriate for that family, so children who come to the Cora Barclay Centre - their families have already chosen for them to speak and not to sign, so spoken language is their choice.

At the Cora Barclay Centre we have about 130 children who are hearing impaired and almost 40 of those children have a cochlear implant, so we do pre-cochlear implant candidacy assessment and then take the child and the family through the process. About 35 of the kids are in early intervention - that's from nought to five or six, depending on the development of the child - and early intervention is located right on the campus of the Cora Barclay Centre, and that's because we know that best practice involves teachers and specialist teachers to manipulate the kindergarten curriculum, so it is an integrated kindergarten. When the children are ready to attend school they're mainstreamed into an independent or Catholic school, which is problematic, and we'll go into that a bit later, but we're not able to service children in DECS schools - Education Department schools.

MRS OWENS: Department of Education?

DR DUNCAN: Yes. When they're ready for school we follow the children to their school and provide the intervention at the school. The reason why we provide the intervention at their school is connected to the funding. We're not allowed to provide it anywhere else, but we fully support inclusion of children with hearing impairment; in addition to fully supporting inclusion, recognising that there must be a continuum of services available and that for some children full inclusion is not appropriate. I embrace the notion that each child is an individual, each family is a unit and each decision is to be made in the context of the child and the family and what is appropriate to them.

MRS OWENS: Can I just ask in which circumstances it wouldn't be appropriate for full inclusion?

DR DUNCAN: It depends. Because of the nature of the disability if the child is diagnosed rather late and language development is delayed three or four years, to put them into a mainstream school may be problematic, and it depends upon the individual child; for example, if you put a child in year 6 but their language is that of a six-year or seven-year-old, they wouldn't be able to cope. The other thing to recognise is that it is well established that children with a hearing impairment - about 40 per cent of children with a hearing impairment have an additional disability - dyspraxia, apraxia, whatever - varying degrees of disability - and sometimes that has an impact on their educational standing, as well.

So in addition to providing therapeutic support for our children we do audiological support. We do family support; a bit of advocacy, although we're not funded to do advocacy. We have transition programs from pre-school to primary, primary to secondary and secondary to school leaving, and we endeavour to provide parent - to parents support, so peer support for parents and peer support for the children, so just recognising that the Cora Barclay Centre teaches children to listen and speak, so we're not a signing program, and parents that come to the Cora Barclay Centre have already made that decision for their individual child.

MRS OWENS: Are most of these children children of parents that are not hearing impaired?

DR DUNCAN: We know categorically that parents generally choose the culture for their child, which is the culture of the family, and so if signing is the culture of the family they choose for their children to sign. Parents who choose for their children to speak nearly all the time have spoken language as their methodology of communicating.

MS McKENZIE: Do you teach signing as well as speech? You said you basically cater for - - -

DR DUNCAN: Our expertise is teaching children to speak and to listen and so our teachers have speech pathology in their background, audiology, and they do additional training in a methodology called "auditory verbal". We do teach kids who are signing - we teach them written English - but we know that our expertise is not signing and so if the families change their mind at some point, we certainly facilitate the transition to a different program - a signing expertise program.

MRS OWENS: And the children that don't end up going into a mainstream school - that you don't deem to be appropriate for inclusion - do they just stay at your centre or where do they go?

DR DUNCAN: No, because we're not a school.

MRS OWENS: No.

DR DUNCAN: It's not best practice to keep hearing impaired children segregated, as you would be well aware, I am sure.

MRS OWENS: Yes.

DR DUNCAN: We're a centre. We used to be a school a long time ago, but we're a centre, and most schools for the deaf have gone to inclusion based programs.

MRS OWENS: You mentioned that there are some children where inclusion is not appropriate. Where do they end up?

DR DUNCAN: In South Australia the only option for them would be what is called a centre for hearing impaired children - a CHIC, for short, which is a cute acronym - and that is in the public school system. Unfortunately that limits the choice for parents. They then no longer have the choice of intervention types. If they feel their child needs a unit they must accept the intervention that is offered to them at the CHIC.

MS McKENZIE: So those CHIC units are attached to government schools?

DR DUNCAN: They are.

MS McKENZIE: Why did you say that sending children to Catholic or independent schools in the way that you mentioned earlier is problematic?

DR DUNCAN: In 1974 and 1985 there was a state review of deaf education in South Australia and the then minister said that the Cora Barclay Centre would service children in independent and Catholic schools and the department school would service children in schools. It actually is problematic for the state because again it limits the choices of parents. Claire will go into it because that's her dilemma; that's part of her story right now.

MRS OWENS: Okay, Claire. Do you want to tell us your story?

MS HARRIS: Yes. I didn't say before, but I am also the parent of a profoundly deaf child who has a cochlear implant. He is now seven and a half years old and he spent the first week of his life in an intensive care unit and fell into what is called a high-risk category, but left hospital without having his hearing tested, so he left hospital severely deaf and this remained undiagnosed for the first 19 months of his life, which has had a profound impact on his ability to learn - on a whole range of things which - you know, his family life, my family life, my working life, the whole lot.

When he was diagnosed he first had hearing aids and he then had bigger hearing aids and he then had various other - I mean, Australian Hearing Services spent probably eight months monitoring the deterioration of his hearing loss. I could have just been sent to Melbourne for a test, which would have told me in five minutes but, according to medical protocol, we had to go through this. He became a cochlear implant candidate when he became profoundly deaf and that operation was done here in South Australia and paid for a children's charity called Variety, of which I am sure you have heard.

MRS OWENS: Yes.

MS HARRIS: I guess what I want to talk about is diagnosis treatment, management, early intervention options, educational options, the lack of parental choice, and the lack of funding equity across the sectors, so it is a whole range of issues, but it will be a kind of personal story to what Jill will say.

MRS OWENS: I think we will find this very useful and informative, so go ahead.

MS HARRIS: Okay. The fact that he left hospital without having his hearing tested - I would like to sue them, frankly. That's how I feel. He is now seven and a half. He can't read. He can't write. He speaks with the language of a three-year-old.

MRS OWENS: Was he prem?

MS HARRIS: No. I mean, he was born at home and taken to hospital the next day and he was very jaundiced and was given a lot of oxygen and various thing which should have been clear indicators to them. Anybody that looks at his medical records would say, you know - I have friends with premature babies; they don't get their hearing tested either.

MRS OWENS: So it's not something that's automatically done for children that are stressed and - - -

MS HARRIS: In intensive care units, they said it is; they say that they have a high risk category. But anyway, they are running a pilot scheme here in South Australia and I know universal newborn hearing screening has been rolled out in New South Wales, but it has taken them a really long time to get to it here. He then has a cochlear implant, which is paid for by a children's charity. I don't understand why that should be the case. Okay, I didn't have medical cover at the time but even so - he was switched on and mapped by the Women's and Children's Hospital. The Women's and Children's Hospital and Cora Barclay are the only two places that run cochlear implant clinics in South Australia for children.

So you have those two choices and they are tied with the educational option that you choose for your child, which is also problematic. So my son was switched on and his initial mapping was done by the Women's and Children's Hospital audiologists and he was badly mapped, so that he was overstimulated, over-amplified, so that he wouldn't wear it unless he was inside the house with all the doors and windows shut. For six months this went on.

MRS OWENS: How old was he at this stage?

MS HARRIS: He had the operation when he was two and a half, and this went on until he was three. I don't know how much you know about cochlear implants, but they have a coil on their head which is the magnet which feeds information through and we kept putting this back on and the ENT surgeon kept saying, "Some kids, it takes them a long time to adapt. You've just got to keep doing this." And that was more waste of time. Eventually I was receiving early intervention therapy from his - from DECS, Department of Education, and she said to me, "You need a second opinion on the mapping. You should go to the Cora Barclay Centre and have him remapped, but that means you have to change your educational option, your early intervention. I cannot come and see you any more. You will have to get a teacher from there."

MS McKENZIE: And you couldn't do it on a fee basis, you couldn't have - - -

MS HARRIS: It was never offered as an option and probably in those days - - -

MS McKENZIE: It wasn't one.

MS HARRIS: It wasn't one probably, yes. So to make those decisions very quickly are very hard for parents because you develop a relationship with your child's teacher who comes to visit you at home. You know, they are not at preschool age, all that kind of stuff, but he was taken to Cora Barclay, he was remapped and, within a week, he was wearing it 24 hours a day and loved it.

MS McKENZIE: Just horrendous.

MS HARRIS: He then had a teacher from the Cora Barclay Centre and I took him there and he went to kindergarten there and he has gone and been provided a service from the Cora Barclay Centre ever since. I knew that once he was diagnosed that I wanted him to learn to speak, because I speak, all my family speaks, but my grandmother is profoundly deaf and it's very hard to communicate with her. She turns 100 today.

So he went to kindergarten at Cora Barclay. The service they provided was fantastic, because his hearing age is measured from the age of three.

MS McKENZIE: Which is when the mapping was fixed?

MS HARRIS: Correct, yes. So he's now seven and a half and his language is obviously very delayed. When I wanted to choose a school for him, I wanted to continue with the teachers at Cora Barclay with the auditory-verbal methodology, which I'd read a lot about and - - -

MS McKENZIE: Could I ask what that is?

MS HARRIS: It's a method that maximises children's residual hearing with amplification and teaches them to listen and to speak. I'm working from the idea that you understand the six-month cut-off period in diagnosis.

MS McKENZIE: I don't.

MS HARRIS: Okay. Universal newborn hearing screening is absolutely essential because research mostly from America - but universal newborn hearing screening is done in Europe, the UK and America - shows that if the hearing loss is diagnosed and intervention is started before six months of age, the hearing impaired child with all things working right, will develop parallel with his or her hearing peers. So you see, I find out that there is a test available that my son could have had when he was born, that he should have had because he was in a high-risk category, and he doesn't have, and it would have had a huge impact on his language development, on his cognitive development, on his social skills, on the whole range. It impacts on every aspect of the child's life.

MRS OWENS: You are saying that this universal newborn screening is starting to take - it's been rolled out in New South Wales.

MS HARRIS: It was rolled out in New South Wales on 1 December.

MRS OWENS: And no other states have picked this up yet.

MS HARRIS: No, there's a pilot scheme running here and they're running it in - Jill would know more than me - in three hospitals.

DR DUNCAN: It's just been finished - five hospitals. But WA has it in five hospitals.

MRS OWENS: So it may move in that direction, albeit slowly.

MS HARRIS: Yes. It's too slow. We've been on a committee to set it up here for bloody years.

DR DUNCAN: February 1999.

MS HARRIS: That is how long we've been talking about it. It's like bashing your head against a brick wall. I would like to take my child to a politician and say, "Right, there you go, spend an afternoon with him." When I need to choose a school for my child, to continue the teachers from Cora Barclay, whose methods I think are the most effective, I have to choose a non-government school. Now, I support the government school system. My older child goes there. I'm a sole parent so I have to send him to a school, so I choose a small Catholic school because they're inexpensive, et cetera. So I now have my son learning about Catholicism, which I am not particularly happy with. I don't see why he can't go to the local state school around the corner and still receive teachers from the Cora Barclay Centre, but this is not possible.

Once he's enrolled it's difficult - you feel like it's difficult getting your child in there. You feel like you don't actually really want to tell them the level of the disability or the service that they need. Once the child is enrolled, he receives - and he's what called a tier 1 child, high-risk. He receives two 45-minute sessions of a teacher of the deaf a week and that's it. And out of those 45-minute sessions that teacher also has to instruct the school aide and also the classroom teacher, which means he is not even getting 90 minutes.

MS McKENZIE: Obviously that needs to be supplemented. What do you do?

MS HARRIS: The school provides four hours of a school aide who is an untrained person. She may have had an introductory day at the Cora Barclay Centre, or somewhere, learning basic stuff about deafness. I have applied to the A.G. Bell Association - Alexander Graham Bell Association for the Deaf in Washington - for a school aide financial grant to buy more therapy for my son in South Australia, because the education of deaf kids here is so appalling.

But the situation is worse: this is just the beginning. Once he's enrolled - it was very interesting listening to those people yesterday - once he's enrolled, if you go and say, "Look, I'm not really happy with this service, with this untrained person that's working with my child" - if you do that, negotiate a curriculum plan, it's not that your grief gets in the way and makes you angry; you know, your grief is consistent and they are separate issues. It's that we know the service those children are getting is appallingly bad, and they don't - or choose not to, or do not have the funds to do anything about it, whatever it is. So you being to feel like a leper in a community that you actually need to feel - you know, like - - -

MS McKENZIE: Included in.

MS HARRIS: Included in, because your children go there. It becomes a big part of your life, so this is a real problem.

MS McKENZIE: If your child had gone to the state school, what would have been the difference in the assistance that the child would have got?

MS HARRIS: There are two issues.

DR DUNCAN: Can I just say that I think we should be cautious about saying what the other system does, because we are not the other system.

MRS OWENS: No, I just wondered; it's a general question: would the child get more resources?

MS HARRIS: Yes, more.

MRS OWENS: If so, roughly how much more.

MS HARRIS: As I understand it, when I was choosing a school for him, I could have sent him to a CHIC centre. There is one at Woodville that way and there's one at Hove that way - and I live that way. It was a cab and probably an hour each morning. I wasn't willing to do that.

MS McKENZIE: Okay, so it wasn't really an option.

MS HARRIS: It wasn't really an option. I looked at Hillcrest, which is the state's oral school, where they teach - but you know, it was also miles away that way. I do know he would receive a significantly greater amount of funding for disability funding, on top of his normal funding. He gets $5000 a year in the school that he's in now. If he went into a DECS he'd get 20,000.

MS McKENZIE: But he couldn't go to Cora Barclay?

MS HARRIS: Cora Barclay is not a school.

MS McKENZIE: Yes, but if you had sent him to a government school, he couldn't go to the Cora Barclay Centre.

MS HARRIS: That is right, and my other concern about sending him to a DECS school was - I'm also a FISA member - that if I put him into a mainstream school he would not receive direct therapy, which is what he really needs. He would have a teacher of the deaf come in as a consultant, work with the classroom teacher, work with the school aide, who are either too overstretched - the classroom teacher - or don't have enough experience and training to do it. You feel like you don't have a choice about where to send your child to school; you know there is inequity of funding and it's wrong and you take your child to school every day and you watch them fail, basically. They don't access the curriculum, and if this isn't a DDA issue, I don't know what is. Do I want him to stack supermarket shelves or have an education and choose a life and - his brain is the same as his sister's.

MRS OWENS: Yes, he should have every opportunity that any other child in this state or in Australia has.

MS HARRIS: And this is the same all over this state. It's just an appalling mess, you know.

MRS OWENS: You've raised three really important issues: there is the issue of your son not receiving appropriate testing while he was still in hospital, there is the issue of lack of choice of schooling for your son, and then there is the issue of lack of resources or inequity of funding. They are the three big issues that you've raised, aren't they?

MS HARRIS: Yes, correct.

MRS OWENS: And they are all very important issues.

MS HARRIS: Yes.

MRS OWENS: The issue about inequity of funding - we are also hearing that from the independent schools sector as well, which is saying that the schools support integration and want these children in the schools, but then they point to the issue just like you have now, that the government schools get a lot more government support than the independent schools, including Catholic schools.

MS HARRIS: Naomi might be able to talk about this, but I know you never believe what you read in the newspapers, but the - believe me, I know it - the federal education minister says non-government schools are receiving too much funding. One of the problems is that this funding is not transparent. We don't know where it comes from, we don't know where it goes to. Because I'm in the process of changing my child's school now, I sit up in bed with a calculator working out the maths on, if I move him into that school he'll attract that much money, how much time of a teacher of the deaf, or of an SSO, or of a special ed teacher can I buy? It's ludicrous. I just shouldn't have to do this, but that's what I spend half my time doing.

MS McKENZIE: You've decided to change schools.

MS HARRIS: Yes, I've just enrolled him into another one.

MS McKENZIE: Another independent school?

MS HARRIS: No.

MS McKENZIE: Into a state government school?

MS HARRIS: I'm trying it, yes, because he has developed other learning needs. I mean, you know - and they don't have a special ed teacher where he is. In the Catholic school, I've just had him psych assessed. They don't pay for it, I've paid for it. You know, in DECS schools they pay for it. They give you bare-bone support.

DR DUNCAN: But the other thing is that they will be purchasing services from the Cora Barclay. Now, you can do that.

MS McKENZIE: That was my next question. Is there a possibility - - -

DR DUNCAN: To deal with discrimination I reckon, but - - -

MS HARRIS: If you find a school principal who will support you in that, and I have found one, they will purchase it. I am very wary about doing it though, because the DECS hearing impairment services say to me, "They may let you do that for a little while and then they will take it away and they will work the consultancy method." Now, it scares the shit out of me, frankly, and I don't want to keep changing his schools, but I have to try it, because it doesn't work where he is.

MRS OWENS: So you've found a school principal who is prepared to support you on this, and it's the school then that goes and purchases the services on a contractual basis.

MS HARRIS: And I wouldn't be surprised, considering the problems Cora Barclay is having at the moment, if the government gets wind of this and stops it, because of the money involved, but I don't want to be quoted on that.

MRS OWENS: Thank you for that. Naomi, you've got a story too.

MS HIGGS: I have, but I don't want to spend too long. Claire actually picked up on a lot of the points that I was going to say, so that's good. I don't need to repeat them. My son actually was born with normal hearing and had normal language development up until he was 27 months old, when he got bacterial meningitis. After 12 days in hospital he was a broken little person who couldn't walk when we took him home. He subsequently had a hearing loss, because the meningitis that he had had a high risk of deafness and we found that he had a profound hearing loss. We were very lucky in that the audiologist we saw at Australian Hearing had said he was likely to be a cochlear implant candidate, because he had had normal hearing before the meningitis.

We had to get a referral from an ear, nose and throat specialist to get his hearing aids fitted and, again, luck was on our side, because the ear, nose and throat person we were sent to was actually part of the paediatric cochlear implant team. Our assessment for his implant candidacy was done at Cora Barclay, and they were just like a lifeline, because we had this broken little deaf person and we had visions of him never hearing, never speaking and suddenly there were people saying, "Hang on, he can have a cochlear implant. There is every likelihood he will." I mean, most people - as you would know yourself, until you're exposed to deafness your assumption is they will sign, because that's the general community representation of deafness.

So he went on to have his audiology services and early intervention provided by the Cora Barclay Centre. They visited us at home, which was sensational, seeing I also had a one-year-old at the time. So then when we came to make the decision on preschool we could choose to travel from Marion to Gilberton four times a week, 35 minutes - - -

MS McKENZIE: Can you tell me how far that is?

MRS OWENS: We're from Melbourne.

MS HIGGS: Sorry, about half-an-hour drive or thereabouts - for a preschool session with him, in which case then I would have to decide whether to go home or stay there and entertain my what was then two-and-a-half-year-old. It was all very complicated. So we actually found that there was an Education Department preschool that wasn't very far from us that actually had a program for hearing impaired children there and had been acoustically treated, so that it was minimising background noises. We then came to the same problem, that we wanted to keep his audiology services, we wanted to keep his intervention services from Cora Barclay, but we couldn't do that if he was in an Education Department kindergarten. Technically we couldn't do that.

Actually the principal at the Cora Barclay Centre, who at the time was very sympathetic and knew that we wanted to have him maintain the support services of the centre when he moved on to school and that this would only be for the term of his preschool, actually allowed us to have services from Cora Barclay Centre on the quiet. We weren't actually allowed to tell anybody we were having services, because it was wrong, it wasn't allowed and it was all very complicated.

MS McKENZIE: I'm sorry, but this is on transcript.

MS HIGGS: That's fine, we've moved on now. Actually, as a side note, that program has actually just been closed, the program we had access to.

MRS OWENS: But again, it came back to having a sympathetic principal who was prepared to break a few rules.

MS HIGGS: Exactly, yes. So he is now in the independent system to enable him to get that service from Cora Barclay Centre. Again, both my husband and myself, who were Education Department school educated, would happily have sent our kids to an Education Department school, but it came back to a matter of what service we wanted to choose for him and we wanted to go - and given that he had had hearing for two years, for us, I guess, the choice was much easier, because he already had speech in its early form, he had a device which gave him the level of hearing to continue that progress, so we wanted the speech to be pushed for him.

MRS OWENS: You didn't want to go to, what was it, CHIC?

MS HIGGS: No. I don't want to upset anybody - the CHIC centres are somewhat interesting in that some of them are primarily oral, some are a mix of oral and auslan, sign language, and some are purely sign. From my experience over the years there can be a change in focus, depending on the principal who is managing that centre over time. There can be, depending on what they see as the most appropriate mode of intervention for those groups of children, which may or may not necessarily be what it was when you first enrolled your child. So there is kind of that grey area.

For him, I guess, he was doing so well in his speech and language that there is a train of thought and, you know, people will argue against it, that if you're struggling to hear in a noisy classroom and you are also taught a manual form of the language, that perhaps sometimes it's easier just to rely on your visual and your signing skills, as opposed to having to use your hearing skills. For us that was a concern because I don't - you know, he may well choose to learn sign as an older teenager, and that is fine, but I wanted to give him the best options early on, which I felt were speech and language for him.

As Claire said, the issue around the independent sector is that should there be any additional services or additional assessment, really that would become the financial burden of the parents. Whereas although DECS are very stretched in their ability to provide those services, there is a capability for you to have that done within that service. As FISA president I have a real problem with this lack of parental choice and the linking of audiology services with education services, that if you change either/or you have to change the whole package. For parents who start on what is a really nightmare journey those first people you make that contact with are just a lifeline, because suddenly they are showing you a way out of the wilderness basically, and you don't necessarily want to always change who is providing that service, based on where you might find yourself in the education sector.

To my mind, I don't see a problem - there may be some children whose parents, as their family, would choose a consultancy model, where they have very minimal direct support, and that is what they choose for their child. I have no problem within the same school there being another child whose the parent says, "I want direct teacher-of-the-deaf support for this child. I want Cora Barclay services." It shouldn't matter what school you're in, you should be able to have what best meets the needs of the child. Surely that's where the DDA comes in, that there needs to be a mechanism in which that is assessed, so that you could go in and say, "Right, these are the reasons why we believe this service is best for our child. Why can't we have it, because this is what we deem is, as a group, best for their needs and meeting their needs?"

MS HARRIS: The funds should follow the child, not the - - -

MS HIGGS: Yes, that's another issue too. FISA, as an organisation, has queried what we see as this lack of funding equity. The federal senate inquiry, I know, looked at that and came back to say that they felt there was sufficient Commonwealth and state funding, and yet no-one can tell us where it is, how much it is, where has it gone and there just seems to be level after level after level of bureaucracy administering this funding. How much of it has been taken up in administration costs I have no idea. If the taxpayers are providing this funding for these children then surely you ultimately should know how many dollars are going to each child, and then there needs to be accountability of that funding. Is it being spent on the child it has been designated to?

We have heard horror stories, from a FISA perspective, that perhaps the class needs a new computer, and because your deaf child might be going to use the computer five minutes out of the day, like every other child in the classroom, they will buy that computer out of their disability funding. So there is that issue of accountability that there needs to be some process in place where the funding (1) is accountable, "Where have you spent that funding?" Secondly, assessing the outcomes of that child, because you could have the best intentions in the world and spend it on that child, but if that is not allowing that child to gain the same education as his or her hearing peers, then really it has not provided the service for which it was intended.

MS McKENZIE: So it has got to be for the child first-up and the - - -

MS HIGGS: For the child first-up and then let's measure the outcomes of that child to make sure that how we are spending it actually is meeting those needs.

MRS OWENS: Could I just say that I think your submission, and also a couple of the independent schools' submissions, have all raised the prospect of the funding following the child, so that the parent can then make the choice that the parent wants to make. I have to say in other contexts that I'm usually quite supportive of that idea. It does promote efficiency. As an economist I think about that. It promotes competition. You should be able to choose - take the money, you choose. The level of dollars would need to be determined, but often in other contexts the dollars are related to the potential outcome or outputs rather than funding the inputs. Then it is up to the service provider to provide the service in the most efficient way. Can I just ask how you get your funding now, Jill.

DR DUNCAN: It's education non-government, non-school funding, so it's the same funding that crippled children get, Down syndrome; that kind of funding. It's education. We do not receive disability funding. That is part of our problem. All other NGOs, non-government non-school organisations, do. So our level of government funding is rather small unless, of course, we are prepared to fight, which we do, but it really kills us.

MRS OWENS: You can spend a lot of your energy fighting and not getting on with the job.

DR DUNCAN: Exactly, and it has - you know, it's soul-destroying to fight for funding when really what we need to be doing is the intervention.

MS McKENZIE: But there is also a real issue, not just about whether funding should follow the child, but it's application.

DR DUNCAN: That's right, yes.

MS McKENZIE: Really, the two things that are being said here is that often the funds are applied for for the school in general, and only a small amount might be applied for for the disabled student. Also, even when they are applying for the disabled student it's not always for their best benefit, if I can put it that way.

MS HARRIS: It's probably worth pointing out too that deaf aid is the only area of disability - the education of kids with disabilities in South Australia where there are two parallel services, the non-government one being Cora Barclay on the one hand and then DECS - the department runs its own. This doesn't seem to make - they just work, it's unmanageable, it's not economically sound, it - - -

MRS OWENS: Have there not been moves for cooperative arrangements, for example?

DR DUNCAN: Yes, it depends on the government of the day and it depends on who the CEO of DECS is. We have endeavoured to have communications, but we just go round and round and round.

MS HARRIS: It's also probably the area of disability that is most political in a sense, within itself, I would suggest, and that probably the history of that also impacts on all kinds of things.

MRS OWENS: There is nothing to stop you having two parallel services, so long as there is some meeting of the minds.

DR DUNCAN: Equity of funding, transparency in accountability - - -

MRS OWENS: And equity, that's right, yes. I mean, there are all sorts of areas where you have parallel services and choice. I mean, parallel services actually can provide you with real choice as a parent. So I don't know if that is the problem. The problem is that you're being denied that choice.

MS McKENZIE: Often the parallel services - it would be helpful for them to speak to each other, particularly with children - the transition from one school to another for example.

MS HIGGS: To pick up on your point, Cate, too, when you asked about children who are signing, Cora Barclay doesn't provide direct auslan support in the independent system. Now, if that parallel system was opened up, then why couldn't the Education Department, who has the expertise in auslan, provide services on a contract basis to the independent schools to children who may be in an independent system who are using auslan.

MS McKENZIE: Exactly, and you're going to get the issues where there are people with particular expertise in one organisation or the other.

DR DUNCAN: Exactly.

MS McKENZIE: It should be possible to have some proper arrangements where both organisations use their skills.

MRS OWENS: It's all about having rational funding and administrative arrangements.

DR DUNCAN: Logical, transparent, equitable, accountable.

MRS OWENS: Yes. We're not calling an inquiry into the South Australian government's administrative arrangements, but we can certainly - I'm really interested in this issue of the funding arrangements, which is slightly to one side on our inquiry, but nevertheless it has been picked up, as I've said, by the independent schools. Could I just raise another issue, both Naomi and Claire, and that is what impact this has had on you in terms of being in the labour market? Have you got a job or have you had to cut back your hours if you've got a job? What impact has it had?

MS HARRIS: I live in Adelaide, because my family live in Adelaide. I work in film, not deafness, and my intention was to move to Melbourne or Sydney when I came back from England. I work freelance from home, because it suits me to do that. I am unable to really - even though he's nearly eight - go and apply for a job and work somewhere; you know, it would just be impossible. It's had, I think, an impact on my career. It's had an impact on my whole family.

MRS OWENS: It really has reduced your mobility, because you want to stay in Adelaide because you want to be near Cora Barclay and keep some degree of stability.

MS HARRIS: And the support that I get from my parents. I no longer live with the father of my children. He found it absolutely impossible, particularly during the six months when he wouldn't wear his processor. It just about did his head in. The stress of living with a child with this kind of disability is such that for me to have the added stress of commuting - living in Sydney, doing that kind of stuff with work - I think would just make me age more quickly than I already am. I keep looking for grey hairs. Save me from this! Yes, the impact - I cannot begin to tell you what the impact has been and, you know, on Edwin's sister - the siblings of kids with disabilities - I'm sure you know about it, but they carry so much responsibility that they just don't need to have.

MS McKENZIE: Yes.

MS HARRIS: She tries to take the stress out of my life. She's just turned 10. She shouldn't be doing that.

MRS OWENS: She's losing her childhood too.

MS HARRIS: Yes, and the work thing is a real problem. I mean, I would have actually liked to have worked and to have done postgraduate studies, but I don't feel like I can do that either.

MRS OWENS: You need a lot of energy to do all three; be a mother and work and care for - - -

DR DUNCAN: But I think if you have the confidence in the intervention consistency and appropriateness for your child with a disability, that would relieve a portion - maybe not all the stress, but it would relieve part of the stress.

MS HARRIS: It would do that; that's very true. The other thing is that part of auditory-verbal therapy is - you know, this dreadful title Parent Guidance, which says you sit once a week with your child in early intervention and still do it so that you can carry on and do those things at home and you have to do that at home, otherwise they won't learn, and deaf and hearing impaired children have great potential to do very well. You know, what would you rather do: spend your time doing that or go and pursue your own career? The decision is not difficult, is it? Well, not for me anyway.

MS McKENZIE: You, of course, are looking to a later time - to later education years and then later to a career for your child. It's not just looking now.

MS HARRIS: Yes, it's very difficult.

MS HIGGS: For me, I guess it wasn't as for Claire. As we said, with that six-month window, Adam had two years of normal hearing, so he was already well on his way. All those brain pathways were already developed before he lost his hearing. For me, I elected not to work until both the boys had started school. As Claire said, I would spend the one hour a week with his teacher for deaf doing his auditory-verbal therapy and then at home I would plan to spend between half an hour and 45 minutes a day with him in a sit-down session reinforcing what we'd learnt. I think the best description I've ever heard of auditory-verbal therapy is narrating a child's life to them, basically, so you spend your whole time running around after them. You know, "I'm going to sort the washing," so you're blah blah blah all the time. This is what you do all day.

MS McKENZIE: It must be very difficult not to transfer that to all the other people you speak to.

MS HIGGS: If you are with a group of parents, you can spot the auditory-verbal parents a mile away with another child, because they just fall straight into it. It's amazing. It's frightening, in fact. I wouldn't have worked in those early years because there was that high level of input in his support. Once both my boys were at school - I'm now working four days a week. What I would say, though, is - whilst, in terms of Adam's schooling, he's doing quite well, in his language development he's doing quite well - I find a lot more of my energy that's being taken away from my family life: fighting these battles; doing this in a volunteer capacity; running Parents of the Hearing Impaired to support other parents; doing the submissions to DDA; doing submissions to other things for parents.

There's an awful lot of parents for whom surviving day to day is about as good as it gets, and they're not going to be able to speak up for themselves and advocate for themselves and so they will, in turn, contact organisations like ours looking for that support. Basically, all the committee members we have now are working, yet in their spare time - between work and children and family - are actually trying to support other families through the same thing.

MS HARRIS: That's very true. I'm also on Deafness Forum, which is a national peak body, as a parent rep. Naomi is right: the volunteer side of it consumes your life.

MRS OWENS: Thank you very much.

DR DUNCAN: We appreciate the opportunity.

MRS OWENS: We really find these hearings extremely informative, but sometimes extremely depressing. We will be looking at all of these issues. We will try and do justice to them. I think we do understand the issue. You've made it very very clear.

MS McKENZIE: We also appreciate the candour with which you've spoken about your personal experiences, which have not been easy. To do that in a public forum is not always easy but it's an enormous help.

MS HARRIS: That's right.

MS McKENZIE: Sometimes it's good as well. We'll just break for a minute.

MRS OWENS: The next participant this morning is the Mental Health Coalition of South Australia, also the Mental Illness Fellowship of South Australia. Good morning and sorry for the slight delay. Would you like to give your name and your position with the coalition and/or fellowship for the transcript.

MR LEAHY: My name is Robert Leahy. I'm the executive director of the Mental Illness Fellowship of South Australia, which is formerly the Schizophrenia Fellowship and I'm also the public officer of the Mental Health Coalition of South Australia.

MRS OWENS: Thank you, and thank you very much for the submission and I understand that you would like to just introduce it briefly for us. We have read it with interest, so go ahead.

MR LEAHY: Just perhaps a few points of iteration. As I've made clear in our submission, that we're not wanting to cover all the issues which relate to the Disability Discrimination Act. I would just like to stress a couple of things though; first of all, that we are very supportive of the existence of the act. We believe it has been reasonably successful in achieving its objectives and has been a valued part of or support for - supporting the participation of people with a psychiatric disability back into the community where they have suffered a long period of isolation. That's the first point.

The second point I want to make very quickly is that psychiatric disability and mental illness are not the same thing. A lot of mental illnesses can be cured. In fact, overall the treatment of mental illness has better outcomes than the treatment of cardiovascular disease and diabetes. Overall, there is a lot of light at the end of the tunnel. There are, however, some particular illnesses like schizophrenia which don't have so good an outcome. About half of those people with a diagnosis of schizophrenia are left with a residual disability, and that's really what I want to focus on here.

The issues that affect people with a psychiatric disability are based around their exclusion from the life of the community. In all disabilities services in Australia that is the primary goal, of getting people reconnected to the community to get them to participate in things and to minimise the impact of an impairment, to reduce that handicap and by assisting the community to accept them. With mental illness or psychiatric disability that's particularly hard and our submission in fact draws upon a survey which was developed in the United States which in fact described or tried to quantify the reasons behind why people had a mental illness and they involved a lot of very ancient, very erroneous myths. So a lot of myths are being perpetuated: it's a result of emotional weakness; it's a result of bad parenting; it's a result of sinful or immoral behaviour or it's relating to the notion that people bring on their own mental illness, which of course is quite incorrect.

The current thinking is that mental illness can be precipitated in some instance by a genetic predisposition which is triggered by a life event like stress, like drug-taking and so forth, but it generally has a biological origin, a genetic predisposition. Mental illness and psychiatric disability are often underrated in terms of the impact. In my submission I've made reference to our cousins in the Mental Health Council who actually give an extensive analysis of the World Health Organisation's analysis of the burden of illness and they point out there that something like 15.4 per cent of the impact of illness in terms of disability-adjusted life years refers to mental illness, and that's very phenomenal.

They also refer to the anticipated changes over the next 19 or so years where they refer, for example, that unipolar major depression will become the second highest ranked type of disease burden. The key thing here is it's not going away. There certainly are better treatments and there certainly are successful treatments but, by and large, for various reasons where the incidences are increasing overall and I think it's going to be a major challenge to our community. What we're stressing in our submission is that the support services that are provided, particularly by the Commonwealth which I've sort of scoped our submission around the Commonwealth, because that was one of your terms of reference, are particularly problematical.

I refer to two of their funding programs which they share with the states. The first of those is the Commonwealth State Disability Agreement where I think you've probably heard that while the states have responsibility for accommodation supports, the Commonwealth has responsibility for employment outcomes. Overall though, the portion of people with a psychiatric disability participating in that program who do have a legitimate claim for support are quite - the proportion is about 15.4 per cent, you would expect. The Australian Institute of Health and Welfare studies are telling us that they have managed to comprise 8.5 per cent of individuals receiving the CSDA-funded services.

We believe that one of the reasons for that is that the myths and the perceptions of mental health are not only prevalent within the community but they're also prevalent within service providers and service planners. There are many service providers who work in generic agencies who would be loath to take on the support of a person with a psychiatric disability, purely because they don't understand the disability. They feel scared. They share that popular myth that, for example, people with paranoid schizophrenia are inherently killers or nasty people, prone to violence and so forth. Hence, the service providers in the community funded by the CSDA aren't particularly interested in the provision of equitable services to people with a psychiatric disability.

The same argument applies to the Home and Community Care Program, although with the Home and Community Care Program it's particularly pronounced because there is a structural imperative within the framework of the program, particularly in the Home and Community Care Act 1985, that excludes funding for other disability groups. It says "except for brain failure". By that, they meant dementia back in those days. What that means is that the HACC Program cannot fund a service which is targeted at a particular disability group. That made sense at the time of its development, because they thought that a system of generic services could be provided which would be efficient, because they could provide to all disability groups. The HACC Program was designed to provide low levels or lay levels of care, not particularly sophisticated rehabilitation - which is excluded - but basically ongoing home support, home care, respite, transport and so forth. Logically, anybody with a disability could be expected to access those services.

Back in 85 what the planners - and I must count myself among them - didn't realise was the difficulty in getting generic services to take up the challenge of providing their services to people with a psychiatric disability. Unfortunately, I've been able to find no recent data. The most recent was a study in Victoria - who gets HACC - back in 1989, as I recall, which said that less than 10 per cent of their population were people with a psychiatric disability. Again, when you look at those figures of 15.4 DALY-type burden, that's quite prejudicial.

What we're saying is that, essentially, there are structural and operational areas of discrimination against people with a psychiatric disability. We believe that requires challenging and, possibly, requires structural modification. The implication here, which I haven't put in the submission, is that while HACC was intended to be a very efficient program - because it was providing a service to all sorts of disabilities - I think that would have to be challenged in order to get services to groups that aren't particularly - I think "sexy" is probably the word, in the sense of being appealing, popular, easy for service providers to relate to and work with, whereas people with mental illness or a psychiatric disability are often people who are alienated, who are marginalised from our community and, hence, not as attractive as a client group. Thank you.

MRS OWENS: Thank you. You said in your submission that you felt that people with mental illness hadn't benefited really from the DDA or had not benefited as much as other groups. We're looking at the act itself, and I was wondering if you had any ideas about how we could overcome that problem and whether you've got any evidence - you talked about the problems with getting services under the HACC Program and under the CSDA. Have you got any suggestions for us about how we can deal with this issue?

MR LEAHY: I think it's a major problem, because it's one which is difficult to legislate or regulate for. I think it falls back into the attitudes of the community and how they're perceived and carried through to service planners and service providers.

MS McKENZIE: Is it an education thing?

MR LEAHY: I sincerely believe it is a community education thing. Until our community accepts responsibility for mental illness and psychiatric disability - there have been a lot of barriers to that acceptance. For example, the presence of stand-alone psychiatric hospitals with tall walls which were targeted for removal in the early 90s as part of the first national mental health plan was the start of that sort of separation of that group. The national mental health plans and strategies had a mainstream philosophy. In other words, people with a mental illness were treated in general hospitals - perhaps in a specialist ward there, but they would be part of it - so mental illness would be treated as any other illness, rather than being segregated into some sort of dire Dickensian hospital.

In Victoria, as I understand it, they've eliminated all their hospitals - apart from the forensic one - so there's a major shift. I think that changes the culture, where the perception of people with mental illness as having a different sort of sickness - I described before some of the myths about that - where it's seen to be like any other illness which requires acute services. The argument I'm making here is the structures are starting to be implemented. In South Australia, regrettably, we still have the stand-alone facility - Glenside Hospital - as well a forensic one.

There have been attempts to close Glenside down and devolve its services into community based facilities and into acute facilities, but that still exists. It consumes something like 43 per cent of the mental health budget and deals with a couple of hundred people, so the efficiency of those services isn't good. Plus it perpetuates that community perception that people with mental illness are special and I think it's, you know, especially horrific - despite lowering the walls which used to have the glass embedded in the top - they've dropped the walls down, but it's still an institution. It is a place of segregation. It is a place, you know, out of the mainstream, so until such time as I think we can get the community to better understand the nature of mental illness - its origins, its biological components, the incidence of it - I mean the reality is that mental illness affects one in five people in our community over a given year, so it's not as though it is a very hidden - well, it is hidden, but it's not as though it's unique. Most families have somebody with a mental illness that they know of - a member or they have friends with mental illness - but the myths are still prevailing and I think that requires a lot more than sort of legislative change.

I think the DDA provides some remedies for it and I do have some examples of its operation. Just the threat of the DDA is often enough to change, for example, an employer's attitude. We were approached by a young man; his wife was employed by a business down south. She was diagnosed with schizophrenia, but she was operating remarkably well: she was one of that 47 per cent of people who go into remission and, often with ongoing medication, they perform brilliantly. She was one of that group. Her disability, in a sense, was not being able to drive too far.

This business - which found out about her diagnosis - arranged to transfer her to the northern outlet, which meant that she had to drive across town - which, although this is Adelaide, it is still a sort of a 45-minute drive - and that was beyond her capacity, so it was basically, "Transfer or we'll sack you." She couldn't drive, so - but fortunately her husband uttered some mean incantations about discrimination and that I think caused the employer in that case to pull their heads in and act reasonably towards this woman. That's the sort of power of the DDA, as it exists.

MS McKENZIE: As a threat - even without actually having to use it.

MR LEAHY: Yes, well, of course, using it generates another set of problems, which I don't want to go into it because I think other submissions have - - -

MS McKENZIE: Yes, many submissions have mentioned the complaint basis that - - -

MR LEAHY: Yes, that's right. It is complex. It does require a lot of people who perhaps don't have the capacity - there probably aren't enough advocates around to carry it forward for individuals, but nevertheless I think it's embedded now in our community, so that the wise employer knows about it and knows its potential, which I think is just as good as having to go through the process of getting an outcome.

MS McKENZIE: What about employers adopting flexible work practices which take account of some of the difficulties of people's mental illness. The example you just gave us is an interesting one because that employer - whether or not the employer knew about that illness - didn't take account of the fact that this lady wasn't able to drive for long distances. Do you think it's an education thing for employers so that they understand the flexibility that might be needed?

MR LEAHY: I am reminded of one of those great leaders; you know, talk softly, carry a big stick. I think it is education which will change hearts and minds but, in the end, I think it has got to be backed up by some teeth. I think many employers are very smart and they can find ways to engineer circumstances which, on the face of it, would not be discrimination but, in reality are discrimination. I think one of the problems we have is that our workforce is over-supplied with staff and I think a lot of employers disregard the cost of training and that sort of stuff and they think they can pick and choose and get people without any special needs or special requirements which they will have to compensate for, and they do it not because of efficiencies. I think underlying that is an unwillingness to accept people with differences in the community - in the workplaces.

Conversely, I have to say - I'm wearing my fellowship hat now - one of our tasks is to provide an education program to try and sort of combat that sort of stigma and I am reminded of an employer who approached us because one of their staff members had a brother who visited his sister; created a significant disturbance and the employer rather than sort of spitting the dummy actually contacted us and wanted us to provide information about the illness and its effects; in other words, he was very supportive of his staff member, the sister.

MRS OWENS: He sounds quite enlightened.

MS McKENZIE: Yes.

MR LEAHY: Yes, it is.

MRS OWENS: But is he the exception to the rule?

MR LEAHY: Yes, I would think so.

MS McKENZIE: Do you think there is a difference where the illness manifests itself after the person has been employed and even perhaps for some years, so that often then the employer approaches it from a standpoint of you having a valued employee who has this issue rather than from, "This is an applicant for employment. We don't even know them and we're scared"?

MR LEAHY: Yes, I would think that's significant. That would apply I think with diagnoses like depression and bipolar, which tend to occur later in a person's life. I mean, the psychotic illnesses like schizophrenia tend to occur or can tend to present themselves in the early adult phase - 16 to 24 is one of the most common ages, and that is actually a time when few people would have established that sort of record of employment and trust with an employer, but certainly with people with a depressive illness, there are certainly - I have been told by some of our sister organisations of people who are working and who give understanding when they relapse.

Just another point I've got to make: the effect of stigma is not just in employment. It actually affects treatment outcomes. The research is telling us these days that the earlier one can treat - that is, on the onset of schizophrenia in particular - the better the long-term results, the less disability a person will have; in other words, early intervention actually works and Patrick McGorry in his epic program in Melbourne has sort of demonstrated that very, very strongly.

So if you can get some of the new anti-psychotic medications into younger people at the early onset stage then their outcomes are much better, but the problem of course is actually getting them into that system or to identify what the problem is. Unfortunately a lot of mental illnesses are undiagnosed, either by family, parents or even by GPs. I mean, the turmoil of teenage years is often a mask for depressive illnesses in the young and something is not quite right is sort of like a code for, "This person is in the very early stages of schizophrenia" - relationships are breaking down; their performance at school is dropping off. Those are the sorts of cues which need to be picked up, but often the stigma of mental illness - I mean, weirdos, loonies have mental illness - prevents people, even families, from taking on the quest for a diagnosis and to get help.

MS McKENZIE: So there needs to be education at that point, as well.

MR LEAHY: Exactly, yes, and so as a result of that they don't get that medication and the outcomes are that they have a more significant level of residual disability after their initial sort of diagnosis in the future.

MRS OWENS: The Disability Discrimination Act has been there now since 1992. I mean, has it got better or worse? You're talking about the stigma. Was it worse 10 years ago?

MR LEAHY: Yes, definitely. I often feel depressed myself over the progress we've made but, when I reflect upon it, certainly there has been a lot of activity and, I think, good outcomes. There have been programs that have taken the message into schools. The beyondblue initiative, which grew out of the - between the Commonwealth and the Victorian government with Jeff Kennett - I think it has really sort of raised the level of awareness of depression in particular, and that's important because that's a high incidence illness.

I mean, there are a lot of people who will be able to have that. I think that the movement away from stand-alone, grim hospitals into sort of the modern acute hospitals, which everybody else goes to, is also eliminating that sort of stigma, as well, so there are attitudes and structural changes which I find can improve the situation. However, it is a slow process and I wouldn't like to estimate what the change has been, but I think it would be in fact a useful study to actually measure that level of discrimination, because it is one of the biggest discriminators and has the greatest impact on outcomes.

MRS OWENS: Yes. I mean, it is very hard to measure discrimination in a really objective way, but the problem we face is there has been an act but there have also been these government decisions like in Victoria, as you said, to de-institutionalise, get people out of mental institutions, so is it because of the act or is it because of government initiatives? What is driving it? There is a real challenge trying to sort of tease all this out.

MR LEAHY: Yes.

MRS OWENS: If we are wanting to look at community attitudes we have a natural experiment between South Australia and Victoria: are community attitudes in South Australia behind those in Victoria? I don't know how you measure them, but because you have still got an institution here, do people here think differently about people with mental illnesses than they do in Victoria?

MR LEAHY: Exactly. Perhaps to try and answer the first part of your question - - -

MRS OWENS: It wasn't really a question. It was just a comment.

MR LEAHY: Yes, it was a comment, but perhaps I'll add some clarification. I think the Disability Discrimination Act came about as a result of the same social forces that were acting to produce the first national mental health plan. I mean, at the beginning of the 80s we had the year of the disability - 1981, I think it was - and I think that triggered a lot of demand and a lot of assertion by the disability community to take their rightful place in society and I think that led to a number of fairly radical changes in terms of support programs; to move out of institutional sort of models of care and support.

I mean, I think you recognise that in your issues paper. I also think that in a sense it was part of that liberation movement that kicked off in the 60s and 70s. I think this came late to it, but I think it has been influencing government policy development and I think it has had that impact in those sort of twin strands and I think when the states and the Commonwealth decided they wanted to have a national approach to mental illness in the late 80s - when the discussions first took place and which produced the first national mental health plan in 1993 - I think that came from the same sort of motivation as the Disability Discrimination Act. The act was trying to regulate or to protect or to provide a guiding light of a model, but also provide some sort of recompense when it wasn't happening. In mental health it was those sorts of notions of community participation which were really at the base of the Discrimination Act - to be treated as anybody else in the community - was the same motivations that got the national mental health plan off the ground.

MRS OWENS: That's an interesting example.

MS McKENZIE: That's an interesting perspective.

MRS OWENS: I was going to ask you about the complaint processes. Under the Disability Discrimination Act it is possible to put in a complaint if one feels they are being discriminated against. We have been hearing that it is, if anything, more difficult for people with mental illnesses to get into that process and there are a lot of barriers. There are general barriers that might apply across the board like potential costs, the stress of doing it and so on, but I was wondering about your views as to what extent those sort of barriers - if you accept there are barriers - are compounded for people with mental illnesses.

MR LEAHY: People with a physical disability are quite able to articulate and to do their own advocacy mostly, as citizens, if the system is geared up for them. People with a psychiatric disability often have a double disability - it's not just the disability of the illness but it also impacts upon their cognitive functioning, or can impact upon their cognitive functioning in the long term as well as the short term. One of the big impacts of the disability is low self-esteem.

Schizophrenia, as I think we all know, has a major impact upon how the brain works and so motivation is affected. People with schizophrenia can barely drag themselves out of bed in the morning; they have trouble organising themselves; they have lost those sorts of skills. The notion of taking on or embracing a system - which is reasonably complex - by themselves is probably out of the question. They need an advocate of some sort to help them through the process.

I have to say that advocacy at that individual level - we do have them and I think you were talking to the Disability Advocacy Service - they do a lot of that sort of work, but I think you will find that they will say that there is a lot they could be doing which they're not able to do. Really it is a matter again of resourcing. There is a particular claim for people with a psych disability to have an advocate, whereas lots of other disability groups or individuals with other disabilities probably don't need them to that extent.

MS McKENZIE: So to take that to the complaints system do you think that the advocate should be able to complain on behalf of them?

MR LEAHY: Yes, definitely.

MRS OWENS: We spoke to the South Australian Equal Opportunity Commission yesterday and discussed the South Australian act which, you are probably aware, doesn't cover mental illness, so anybody that did have a complaint would need to go through the HREOC Disability Discrimination

Act processes. Have you personally had contact with anybody that has either felt inclined to go through that process or has gone through that process?

MR LEAHY: No, not personally.

MRS OWENS: We're interested to get as many case studies as we can of people who may have had a problem of discrimination and wanted to take it further and we're trying to follow up the ones that didn't, as well as the ones that did.

MR LEAHY: Yes. As a practice we would refer our constituents to Disability Action because that's their specialisation and they would - - -

MS McKENZIE: They might refer them on or whatever is the - - -

MR LEAHY: Yes.

MRS OWENS: But you haven't referred anybody on to them?

MR LEAHY: Disability Action, we have.

MRS OWENS: You have?

MR LEAHY: Yes.

MRS OWENS: So if people have come to you and said, "I've got a problem" then you have referred them on

MR LEAHY: Yes.

MRS OWENS: So you don't give advice about what they should do but say, "Just go to Disability Action and they'll give you advice"?

MR LEAHY: Yes. Not advice per se, but we would just sort of set the context of what their entitlements are and suggest they contact Disability Action if they wished to pursue the matter formally. We often do a bit of informal advocacy ourselves, if that's appropriate. For example, we will try to resolve issues without it turning into a complaint. We see problem solving as being a very useful role we can play. Often people with a mental illness aren't communicating precisely what their issues are. They often get into trouble because of the nature of the illness - like their lack of motivation in terms of paying bills and having money on hand, and that sort of thing.

If the person is agreeable we would refer them but it's up to the public trustee to take over their finances and to control that. If they have, for example, a gambling problem, they sort of ration that. We would suggest that they get Centrelink to take deductions for their rent and bills and their utilities out of that.

MS McKENZIE: So that's very practical facilities.

MR LEAHY: It is, yes, so rather than having to get into a situation where the person is evicted or a person has a major debt claim against them, we would try to put small systems, small arrangements in place to resolve those sorts of issues.

MRS OWENS: What if they had a problem with their employer? If their employer was about to sack them or - - -

MR LEAHY: In the case I gave you before, where the husband had contacted me, I gave him advice and told him what the options were and what his wife's rights ought to be in that sort of instance and gave him the Disability Action contact and left him to it. He came back later and said that he had simply dropped the Disability Discrimination Act and things were hunky-dory.

MRS OWENS: So you told him about the Disability Discrimination Act?

MR LEAHY: Yes. As I said, it is a very useful part of talking softly and carrying a big stick.

MRS OWENS: They are all my questions. Have you got anything else you would like to raise with us? Again, that was very complementary to what we heard in Canberra - whenever we were in Canberra - - -

MS McKENZIE: Yes, excellent.

MRS OWENS: - - - talking to Prof Hickie and to Dr Grace Groom. I think it is just building up a picture for us of these issues, which are quite special issues. We're dealing with a lot of special issues, but in terms of our interest in the act and people's capacity to use the act it is particularly interesting for us to find out what it means for particular groups. We're also interested in the comments you made about access to services and some of those other issues we are going to be acknowledging in the report. Some of these issues are - - -

MR LEAHY: Are peripheral.

MRS OWENS: - - - a bit borderline in terms of our own terms of reference, but nevertheless they are important issues. What we will be doing in our report is saying, "By the way there are a number of other issues that have been raised with us which need to be thought about."

MS McKENZIE: Yes.

MR LEAHY: Yes, that would be good. Thank you.

MRS OWENS: Thank you very much for your submission. We will now break and we will resume at 11 o'clock.

MRS OWENS: The next participant this morning is SPARC Disability Foundation Inc. Good morning, and welcome to our hearings. Could you please give your name and your position with the foundation for the transcript.

MR CHRISTIE: My name is Paul Christie. I am the project development manager for the SPARC Disability Foundation.

MRS OWENS: Thank you, and thank you for the submission. As I said to you off transcript, yours is the first submission that has talked about issues relating to sports, arts and recreation, so I found it very interesting to get into what is a new topic. We have had a lot of other interesting submissions, but we look forward to listening to what you have to say. You said you would like to make a few introductory comments to introduce your submission.

MR CHRISTIE: Yes, I can do that. I will provide a bit of background first about the SPARC Disability Foundation. SPARC was set up by the state government back in 1990 to provide increased opportunities for involvement and participation by people with a disability, in sport, art and recreation. We only operate in South Australia.

It is in the broadest context of disability. I suppose we do it in three ways: we like to facilitate increased opportunities and we have a grants program that we operate. In other words, we provide money to sport, art, rec, community disability groups to try and increase that involvement of people with a disability in sport, art and recreation. We also have an education program, a sort of disability awareness program, which we run on behalf of the Australian Sports Commission, which is obviously about sport and physical activity and we educate, provide training for coaches, for volunteers, for officials, for teachers. So that's quite an extensive program and has operated for nearly seven or eight years.

We also identify gaps and needs out there in the community and have developed a range of responses. We usually do that in partnership with either the arts industry, the sports industry, I suppose, the disability community and what we are trying to do is develop those partnerships where we believe it's about - the terminology is "community inclusion" - where if a person wants to play tennis that tennis club should be able to provide opportunities for everybody in that community and that includes people with a disability. I suppose it's about that tennis club, or the sport of tennis for example, developing pathways.

In other words, if somebody wants to participate in tennis they should be able to do that from fun and recreation through to the elite level. That requires everything from coaching to competition, providing introductory opportunities. I suppose that's the philosophy which we base our work on - that is, the tennis community is responsible for providing tennis opportunities for people with a disability. We are trying to work with Tennis SA for them to develop - in this case they have developed a DDA action plan - and various strategies to improve access in a range of areas across South Australia for people with a disability.

I suppose that's the context which we are coming from. As a disability charity we identified, when the DDA was first released, that it was incumbent on us to be working and showing a bit of leadership to also develop a DDA action plan. We lodged our plan and I have a copy. We lodged our plan dated 1 September 1997 with HREOC and, in the submission, it refers to "We monitor that via fortnightly staff meetings, we try and update that through the staff input. We also then feed that through to the board who get an update and review that on a quarterly basis." That is the mechanism we have used to keep on top of it, if you like.

MS McKENZIE: So that is looking at how you are going and should there be some changes made.

MR CHRISTIE: That's right. The cornerstone of the DDA is about developing action plans and strategies. As a disability charity we have also been in a position to - we have not only developed our own plan, but I worked as a consultant and helped another organisation which was called Living

Health. Living Health doesn't exist now, but we did a full process with Living Health with its staff, disability awareness and developed a draft DDA action plan for that particular organisation, plus we've done various disability awareness sessions for a range of agencies. I think I listed in the document a couple of councils that we worked with to help them develop DDA action plans. So we've provided both advice and support.

We have in fact also funded an organisation in the sport rec area to development DDA action plans - in other words, for somebody externally usually, to help them complete that process. That's the biggest dilemma with a lot of these organisations - not so much the larger ones, like the cricket, football and tennis, but particularly smaller community based organisations that are usually run by volunteers and don't usually have firstly, the expertise or the resources to be able to go through this particular process. Unless they are able to secure external expertise, and that usually also means money, they would be hard-pressed - they might be able to develop the plan but the difficulty is also then to keep that monitored - who does that, who is responsible - because unless it is done at a senior level, and that's the board of management or the chief executive officer, it is very difficult to maintain that quality control, that input to that particular process about keeping on top of the various strategies.

That's a quick overview. In my submission that I referred to the DDA, or the action plans, isn't compulsory. We thought it was a good strategy to do, because of the nature of the work we're in. I suppose there's arguments for and against. The weakness we found was that there was no other information out there that you could get as to how you go about this process. Different organisations do it in different ways. Some can do it internally, have the expertise, some don't. HREOC did produce some booklets. I think at the time the Norwood Community Legal Service offered some advice about how to go through this process.

MS McKENZIE: You really felt you still had to work it out for yourself.

MR CHRISTIE: We had to work it out for ourselves basically. We set up internally, a sort of little staff reference committee and did bring in some expertise from the community to help guide us, like a reference group, to go through the process and ran disability awareness sessions for our staff, and board and so forth. But probably the process from saying yes to actually having the plan probably took six to nine months; it took a period of time to do. At least we had some experience in the disability area so - - -

MRS OWENS: So you're tuned in.

MR CHRISTIE: We were tuned in. My worry would be that at the local Tennis SA, or a community group - that's where they would struggle. They would have to get external expertise in most cases.

MS McKENZIE: And that's costly, of course.

MR CHRISTIE: That is a costly exercise. Unless they can get money - they could have got it in some cases from SPARC, or from the Office of Rec and Sport, or through Arts SA through the state government - they would struggle to complete the process. In fact what has happened in the last three to five years - a lot of the government departments do have their own DDA action plans themselves, but some don't - but in fact are requiring agencies that get money from them that they should be developing DDA action plans to get the money. But the state government department themselves haven't - - -

MS McKENZIE: So it's a case of don't do what I do, do what I say.

MR CHRISTIE: That's right. That's a bit hypocritical, but that's what in fact is still occurring.

MRS OWENS: Can I just go back one step. You talked about HREOC producing booklets. Didn't you find those booklets very useful when you were developing your own plan?

MR CHRISTIE: They produced one for government agencies and one for non-government agencies, as I remember. I did use it for the steps, probably the six or seven steps that were within that, but there wasn't still a lot of detail. We did it fairly early in the bit. There weren't many others. If you clicked onto HREOC I think at the time probably two were lodged before ours, two or three anyway, so there wasn't a lot of other examples. I used to find the best way to do it is to say, "Well, this is how they have gone through the process. They set up a reference group." Key things, like you need a reference group, you need at a senior level, taking responsibility for the implementation of that plan, otherwise it won't work. Unless you can get the board approval and understanding it is very difficult for that organisation, at a project level, for that person to influence what the board might decide. Again, if it comes down to spending resources that's where the CEO and the board of management would need to make those decisions, to plan the thing over a period of time in accordance with their budgets.

MRS OWENS: I wonder if things have improved, though, for others trying to put a plan together now. When you did it it was five or six years ago.

MR CHRISTIE: Definitely.

MRS OWENS: Maybe now, because there's a lot more plans out there, people can get access to a range of different plans and maybe HREOC has improved the material that has gone out over the last five or six years.

MR CHRISTIE: Definitely. Also there are a lot more consultants, if you like. There are a lot more people out there who will provide advice and support. I suppose by looking at examples, as I said, if you are a local council you want to see what other local councils have done; if you're a sports group you want to see what other sports groups have done. The difficulty is - we, as a charity, have run the odd workshop, if you like, about how to access our money in terms of priorities - it almost needs on a regular basis - I suppose then who takes responsibility? Is it the state government, is it the Commonwealth or is it a joint initiative where every so often it should be, "If you want to complete this process, here is the how to. Here are some examples, some case studies." You know, people can come in and talk about what they have done and how they have gone, what has worked and, probably more importantly, what hasn't worked. As I said, it's a bit better now, particularly in the sport, art and rec area, because, as I said, both the office of Rec and Sport and Arts SA are saying to their clientele who apply for money that they must be working towards developing a DDA action plan.

MS McKENZIE: What hasn't worked?

MR CHRISTIE: I think the hard bit is still - our dilemma is the monitoring. Are we doing a good job? What we are saying is, is that the right way to do it? Is that the correct thing to do? Hopefully we're on the right track and it's a bit of trial and error. That is one of the weaknesses. But I think the fact that people are actually thinking and talking about actually developing policies and strategies, that's the tick. I suppose in all things it's relying on the expertise and who controls that. In a volunteer sense it's very difficult for them to maintain that energy over a long time. If the key person leaves the organisation the DDA - I know a couple of sports in this state where they had actually very detailed DDA action plans fully supported by the board, but once the key driver of that process left, the thing fell over because the next CEO that came in had no interest. So it wasn't embedded into the board of management in terms of, "This is a process we're going to continue to follow," just because the personnel changed.

MRS OWENS: You said earlier it's not compulsory. Do you think it should be compulsory to produce an action plan?

MR CHRISTIE: My short answer would be no, but I think there need to be some sort of incentives to say, "Look, this is the right thing to do." The way we sold it to our sport, art and rec industry is to say, "Look, this is about more members. It is complying with the legal side, but we think here is a marketing tool. This is 20 per cent of the population that you're probably not getting, so it's important for you as a member based organisation. It's about maintaining the health of your sport or your arts group or your community group."

MS McKENZIE: Why do you think it shouldn't be mandatory?

MR CHRISTIE: I think it becomes resentment. That's why I think the incentive way is better than, "You will do this through legislation." It's about education. It's about providing support and education to the community to convince them. I try to do it through sport and physical activity by media campaigns. Sometimes they work, sometimes they don't, but it's changing the attitudes. Everything we're talking about is about attitudes. It's about changing attitudes to people with a disability, in other words, whether it's sport, art, rec, transport, employment. It's trying to provide a community which is accepting of all people and, I suppose, how you best do that. I don't think it's by saying, "You shall." I think that creates resentment, but we can encourage, educate, promote. With financial incentives, they're already doing that. Government departments, through arts and sport - you will not get a grant unless you do develop one. That's an incentive.

MS McKENZIE: A good incentive, yes.

MR CHRISTIE: In the last page of my submission I talk about, "The problem has been to implement change and to improve access that is sustainable." That's what I said. It's trying to maintain those strategies and embed those within the boards of management. It's the same for business. It's smart business practice. If you run the X, Y, Z rec centre or Santos, if you want to improve your business and if you're not promoting to all in the community - or the petrol station - who are using your services, you're missing out. That's the incentive I see - it's around that. It is not only good for you and morally the right thing to do, but here are some things that you can do that will help you improve your tennis club membership or improve your sales. I suppose that's less of the big stick, which is the more desirable. I think, in terms of sport, art and recreation, we say, "Look, it's about funds. It's about enjoying things and having a quality of life, and that should be equal to everybody, the same as health and education."

I think the other one was - in the early days when those booklets came out, I think it would have been healthy to have some sort of workshop or say, "Well, here are some ideas as to how you might go about doing it" - some actual practical things do to. I suppose that's where we and other agencies now are providing that to sport, art, rec community disability groups. In fact, it's interesting when you talk to some of the disability groups. They say, "We are a disability group, we haven't got an action plan," and I find they should be the ones that are showing some leadership and doing those sorts of things.

MS McKENZIE: You talked about education and plans. What about the complaints process, which also is a component in the DDA?

MR CHRISTIE: I think that's the weakness, because it relies on the person with the disability lodging a complaint, and people are reluctant. Why should they have to go through a lengthy, timely, costly process, possibly, to say, "Look, you've wronged me, you've excluded me, you've discriminated against me." I think in the documentation I said, "The complaints process of the act puts the onus of responsibility back onto the person with the disability or their advocates. This process can be daunting and prohibitive for most people." I haven't got any solutions to that, but I think that's a difficult thing for people to do.

MS McKENZIE: You'd rather see things sorted by these other means?

MR CHRISTIE: Yes, conciliation, negotiation. The big stick really can only come from government - Commonwealth, state or local - "You shall comply." Again, you negotiate that. I think that's where, in all of this, the people who have been leading the - particularly in this state, lots of local councils have actually developed DDA action plans. I would suggest, you know, 70 or 80 per cent would have gone down that path. I think it's closer cooperation. They say monitoring - a lot of them - and planning approvals are local council.

I think local, state, federal need some sort of partnership here to say, "Look, if this is going to work, they're the three key players in the government process." How can they work to improve, I suppose, the delivery of services for people with disabilities generally? Not just sport, art and rec, but everything - you know, transport, employment, training and those sorts of things. For instance, in TAFE, they provide a lot of training, vocational, educational, schools. The mix has got to be those three tiers of government, otherwise it doesn't work. To me, if you were monitoring it - educating it - they've got to work out roles and responsibilities between those three tiers of government.

MRS OWENS: I was going to come back to the complaints process. You gave some very compelling arguments about the problems of people with disabilities going through this process. Quite a number of people have said to us why not have a system whereby individuals go the organisations - advocacy organisations or others - that then put in complaints on their behalf, or maybe advocacy organisations or groups, find a systemic issue and just initiate the complaint.

MR CHRISTIE: I think that's happened in this state previously. We've got Disability Action and I think Disability Action has done that on occasion, where they've helped support the person. Whether they've actually gone through the whole process, I'm not sure, but they - - -

MRS OWENS: But there's a different between supporting a person who's - - -

MR CHRISTIE: And actually doing it.

MRS OWENS: - - - still initiating a complaint or saying, "Okay, we're going to run a complaint," and keep the individual out of it to some extent, or just run a complaint on an issue that may affect a whole range of people that they're dealing with.

MR CHRISTIE: It's like giving a brief to a lawyer or something, "Here is your advocate, here is what I'm saying," and then they become the negotiator with the organisation. If the resources were there to do that, yes. As long as the individual or a group of individuals - we may have a class action; there might be more than one - still have an opportunity to have their say. I suppose that depends on how the process is handled and in what sort of forum that's done. If it's across the table, I think the person needs to hear what's being said and, "He said, she said." You can still do counselling, but if somebody is then representing you, you want to get that feedback and you need to hear what's being said.

How that process is done - is it a formal submission? "We submit that to HREOC." Who's the repository for those complaints? Again, it could be sorting that out between government and community agencies as to who takes what roles and responsibility. As long as the individuals still have their input and say, whether that's briefing the organisation that may take it over, but also having input throughout that process.

MRS OWENS: Some individuals mightn't want to have an input. They might, for various reasons, want to stay right out of it.

MR CHRISTIE: And that's their choice.

MRS OWENS: They may not be well enough to be involved.

MR CHRISTIE: I think that then has to be their individual choice, but it should be - "If you want to, it is still open for you to be part of that process and what part you take in that process."

MS McKENZIE: Have there been any changes in the attitude of sporting and recreational organisations to the inclusion of people with disabilities in their mainstream activities over the last, say, 10 years; in other words, since the DDA has been around?

MR CHRISTIE: I think so, definitely. Just from the work that we do and dealing with that range of sport, art and rec disability groups, there is an improved attitude. Do you put that down to the DDA or other others - - -

MS McKENZIE: That was about to be my next question.

MR CHRISTIE: Because of the work that, as I said, the government agencies have done - and that's both state and local government in this state - I am 100 per cent positive that the lot has improved and the educational process goes on. We say you educate and try and change attitudes as young as possible, so we're doing a lot work with not only teachers and coaches but kids themselves and giving them the right attitudes and information about, I suppose, the world around them. The government agencies - it's been interesting, because it was all of a sudden a big stick back in about - even though the DDA was in 1992, it probably took three years before the state government and local councils actually grasped that it was their responsibility to actually help drive this, but unfortunately - as I said - probably resources hindered a lot of it.

A lot of it's about information. If they haven't got the information, how do they find out about the DDA or how do they find out about improving access to their facilities? Just purely in terms of physical access, if you've got to put the ramp in or the disabled toilet in, they have no idea how to go about doing that, so you actually have to tell people that there's money available to do that, both councils and state government then working closely together to say, "Look, there is money for us to help your club become more accessible." Then it's about telling people with disabilities, "This tennis club is accessible," because unless you tell them that how do they know?

MS McKENZIE: They don't know. That's right.

MR CHRISTIE: I suppose what they've done in this state, even for the bigger sports, rather than say they have 100 tennis clubs - I'll use tennis again. I'm not sure how many they do have, but realistically they can't have 100 clubs accessible, so what they've done is identified clubs north, south, east and west of Adelaide and tried to get them up to scratch first and then build on that. They started with 10 coaches. Now they probably have 40 coaches who are trained. It's a slow process that they have to work through and it takes time. If you're north, south, east and west, but you live in Tea Tree Gully and the closest tennis club that's accessible, in terms of broadly accessible - are they going to travel the distance?

A lot of the barriers are still around the lack of information, the cost of the activities and the transport. They're the barriers, in terms of they've still got to make choices how they spend their time and also how they spend their money. We say it's an important balance in life. You can have all the education, training, they're working and have the roof over their head, but the balance is you need to have some fun, social contacts and a quality of life and a lot of the tools sometimes for that is sport, art and recreation for a lot of people. Some don't want that, but that's, again, about individual choices - about what we choose to do in our spare time.

MRS OWENS: You said that there was a virtual absence of education provided by HREOC in South Australia. As you've been going through your presentation today you've raised quite a number of examples where there is lack of information, or maybe inadequate information regarding how to set up action plans, feedback on action plans, information about how to do specific things, like put in ramps and so on, and you said that your organisation fills some of those gaps by providing information. I suppose it's really a matter of: where should the responsibility lie and what more could HREOC be doing in South Australia?

MR CHRISTIE: I think that's what I said earlier. I think that is where it has to be sorted out. HREOC is a Commonwealth piece of legislation. They need to have the overall monitoring at that level; the state could take certain responsibilities and then, at the local level, local council. So it's about dividing that level of responsibility down because at the local level the closest people to the action - and that's the local tennis club or the planning approval to build a new building - is with local council. They're closest to the action. I suppose, when I say "education" it was particularly in the early stages and I think that's where they had to be more proactive and now a lot of that responsibility at the local level is being done by probably state government departments rather than at the Commonwealth level, whether it's transport or arts or sport. They are realising that for the betterment of the community it's in their best interests, particularly if they are giving out money - they have a responsibility to improve access to all services and facilities.

MRS OWENS: But, Paul, there is a bit of an issue when you divide up the responsibility in that way because sometimes things can fall through the cracks. The state government can think, "It's HREOC's role," or leave it for the local level or individual organisations, and so nothing really gets done. We got a very good example given to us yesterday of something that is happening at the state level and that was the Equal Opportunity Commission got a web product for clubs which - - -

MR CHRISTIE: Playing by the rules.

MRS OWENS: Play by the rules, which I thought was an excellent example where they've taken the initiative to do that. But I don't know if there is any equivalent product elsewhere. They said it's now a national product, but it really is - the motivation has to bubble up and what I'm really wondering about - that's quite a hit and miss approach. I have to congratulate them for doing that, but it could have just as easily not got done, it's just because of individual initiative that led to that.

MR CHRISTIE: That's right.

MRS OWENS: I am wondering if there is some more formal way in which HREOC could be setting some guidelines - both providing education themselves but saying, "This is something that could be done at the state level, and this is something that could be done by individual organisations."

MR CHRISTIE: I think HREOC have to take - they are the ones that have to take responsibility; they are the ones, I suppose, in the act that are listed and should be taking responsibility. How they negotiate down who does what and who takes - they are responsible. They are ultimately responsible for want of success or failure, if you like, of this piece of legislation.

MS McKENZIE: But also, in allocating responsibility, you don't want to stifle initiative.

MRS OWENS: No.

MS McKENZIE: It is a bit of a balancing act in a way, isn't it? The equal opportunity commissions in the various states have got a statutorily defined educational responsibility. But that of course applies only within the state, but that's why they do what they do.

MR CHRISTIE: I know the Equal Opportunity Commission has done some work with - I haven't been that closely tied to them. Again, in terms of delegation of powers and responsibilities, to me it's to be sorted out. I think the Commonwealth needs to negotiate with the states to say, "We're happy" - the education, as you said, can be - these days with the Internet and web sites you don't necessarily need the hard copy these days. But if you're looking for examples you can now go to the HREOC web site and you can push a button and there is the list of all those that have been lodged. You can actually open them up. You can download them. It's a bit easier now.

I suppose what people want the relevance for - I'm a sports group so I want to hear and see some sports examples. As I said, it's about then dividing up almost the industries. If you want information about transport, here are some case studies, some examples. How that's then communicated - they all should be doing it. Local council should be doing it at its local community level, because they are dealing with the community clubs. State government - I suppose - is the bigger picture in terms of the infrastructure, whether it's the bus system or the schools or the hospitals. There are various layers and I suppose it tends to relate to trying to change. What we're trying to do realistically is change what's out there to be improved access for people with a disability in all the areas.

It just happens to be, I suppose, in this state, sport, art and recreation has had a fairly large focus. But there are some areas - the buses and transport systems - they are slowing improving but it takes governments and people with budgets to say, "We can phase this in over two years or over three years." A tennis club, to do those sorts of things - they are reliant on other people to give them the money to make that change. Sometimes it's not a lot of money; sometimes to run the disability awareness sessions for officials and for people within those clubs is a small cost, but it's for them - it usually takes somebody within that organisation to say, "We want to be part of that."

So it's about saying, "This is good for your club." As I said, to put it back on to the community to say, "We think this is a good idea; this will help your membership, this will help your sport to grow because you are not targeting - you are not reaching the 20 per cent of the population that you should be." It's probably more disadvantaged if you're a person with a disability in country South Australia or regional South Australia, it is even more difficult to access services and have choices about what you can and can't do. So my fear is, how do you get that information out to country areas? It's almost like the travelling roadshow. I know, for instance, the Office of Rec and Sport here do that sort of thing. They have to go on the road; they have field officers. So it's about those field officers being aware of what is around - what money is around and that includes for things to improve access for people with a disability. So usually it's who holds the information that has the power. In other words, those clubs that can access and have - some people don't have the computer on their desk at the tennis club because they can't afford one.

MRS OWENS: I just have one other issue. You may not have an answer to this but you seem to be quite dubious about introducing disability standards into the area of clubs and sport and recreation. You mention in your submission that most clubs and groups would try to comply with minimum standards to achieve their goals. We're looking at this issue of the coverage of the act and, at the moment, some areas are not covered in terms of standard development in the future, so I'm just wondering what is your view about whether standards should be developed in this area.

MR CHRISTIE: I think they probably can be. As I said, the choice is due - if you are going to write something into legislation, is it the minimum or the maximum? It's like there are standards set for everything in terms of whether it's building codes - you must be such-and-such wide and high. It is how prescriptive you can be and what resources are then put towards that. I suppose that's the balancing act in terms of, if you are going to write up standards, what people tend to do is, "The minimum is that you do this." But they should be aspiring to provide everything. I suppose it's somewhere in between. It's almost like grades. If you are the Festival Centre, for instance, you should be complying with everything because you've got the resources to do that. If you're the community theatre group, you just haven't got those resources. I suppose they are the grades; it's about the big and the small; the community and the infrastructure. To me the grade is the ability to be able to make change because you've got the resources to do that.

MS McKENZIE: So there is a minimum amount, but your view is that if you're bigger and you've got the resources, you should do more than the minimum.

MR CHRISTIE: And you should be doing it more quickly. In other words, instead of the five-year plan to implement access to the Adelaide Festival Centre, they should be able to do it in three.

MS McKENZIE: And that's hard to provide for in a standard.

MR CHRISTIE: That's right. Most people think it's still about physical - it's still about buildings, it's still about that sort of access, but to me it's a lot about - it's still about attitude and it's communication and information. They're the things that people struggle with. The physical they can understand, because they can visualise it, or picture it or say, "Yes, it needs to be a certain width or height, or we need a ramp here or the light switch needs to be this high." But when it comes down to the common belief that if you're in a wheelchair you have some sort of intellectual disability, you talk down to people or you - it's about changing attitudes and giving information to people about how they view the world. The unfortunate thing, I suppose, is that it all comes down to what people think when they see a DDA action plan and it always comes down to the physical stuff first. We say it's not that. It's about education and changing the attitudes first.

MRS OWENS: I think that's consistent with your views on action plans, too.

MR CHRISTIE: Yes.

MRS OWENS: Good, thank you very much for that. Is there anything else you'd like to tell us, Paul?

MS McKENZIE: Excellent and thoughtful submission.

MR CHRISTIE: No, I don't think so. I suppose in summary I think the DDA has been beneficial. I think it has made changes - probably not as quickly as we'd like to see changes - but I think it's more about cooperation. Any piece of legislation - I think it's still about the communication and responsibilities between the three tiers of government and, at the end of the day, it's about trying to improve everything out there for people with a disability. It doesn't matter whether it's - in my case it's sport, art and recreation, but it's the transport, the health, the education, the employment opportunities and how do people access that information. I have nothing further.

MS McKENZIE: That's good.

MRS OWENS: Thank you very much.

MS McKENZIE: It's very helpful.

MR CHRISTIE: And good luck with your task.

MRS OWENS: Thank you very much. We'll now break just for a minute.

MRS OWENS: The next participant this morning is Mr Maurice Corcoran. Could you please repeat your name and the capacity in which you're appearing, for the transcript.

MR CORCORAN: Yes, it's Maurice Corcoran. I'm here today from an individual's perspective and my personal experience and use of the DDA and involvement as a representative of people with disabilities, and it's not in my current work role. It certainly is not in my role as a representative of the Department of Human Services, nor the state government of South Australia.

MRS OWENS: Good, thank you. Thank you very much for appearing today, Maurice. We appreciate you coming as you have had a lot of experiences in various capacities in this whole area and we value getting some insight from you. But I will hand over to you. You've given us some material this morning and some slides, and I thought I'd hand over to you and you can run us through what you've got and maybe ask you questions as we go.

MR CORCORAN: Thank you, commissioner, that will be great.

MRS OWENS: You can call us Helen and Cate.

MR CORCORAN: First, I would just like to acknowledge where I am presenting in the meeting here today on Kaurna land. I think it's an important to thing to acknowledge our indigenous population.

MRS OWENS: Thank you.

MR CORCORAN: I would also like to, as a starting point, congratulate the Productivity Commission on their discussion paper. It's a really useful document for a whole range of reasons, but it's a really good document which adds value to a lot of discussion around disability discrimination and the usefulness of and otherwise of the act and some of the challenges that we have ahead of us.

So I would like to talk a little bit today about my experience as a complainant under the Disability Discrimination Act and what the process was and the consequences were for myself as an individual and some of the pluses and the stressors involved in that process. One of the most significant cases I was involved in was when we lodged complaints against the South Australian state government in relation to the lack of access to public transport back in 1994. That was when I was actually in a position as coordinator of a program at Disability Action, an advocacy agency here in Adelaide which you heard from yesterday morning.

My role was to set up a statewide network of volunteer advocates and that those advocates have personal experience with disability. It was an empowerment model to try and encourage people with disabilities to use advocacy skills to better represent themselves but also for other people in similar circumstances. It was a fairly new concept for myself, coming from a social worker role - my previous work was as a social worker - so the adversarial or advocacy role was something new and challenging for myself.

When we were looking at the whole issue of public transport back in 1994 we really had to do a lot of research to try and find out what was actually happening overseas in terms of access to public transport. There wasn't a lot that was proactively publicised by peak bodies about some of those changes that were happening overseas in Europe and so we had to do a lot of that research ourselves. That in itself puts a lot of strain on small agencies and resources. When we lobbied the state government during the 1993 election - at the end of 1993 - we got commitments from the then opposition party who ended up winning government, but our concerns became more evident in the beginning of their term of government when it seemed that they weren't addressing that issue we wanted to carry out.

We went through a process of writing and trying to persuade government in a more conciliatory, more reasonable approach until such time as we felt that we had no alternative but to actually go more public about the issue. It was at a time where the government were launching new badges, or new colour schemes et cetera, for their buses here in Adelaide and they had open days at all the bus depots where we ended up quickly organising a protest and blockading one of those bus depots. We signalled then, at the time, that we wanted access to public transport and this problem was not going to go away; it was a major problem for people with disabilities, which is why we also threatened at that time that we would use the Disability Discrimination Act.

We were hopeful that just the threat of the act would bring about some positive change. We got lots and lots of attention through all the media on that weekend about our plight and the fact that a lot of people couldn't get onto transport, so it was an educative sort of process as well for the community. Following that, when we discovered that the South Australian government had an order of 50 buses that were going to come into Australia but they had not made provision to actually put ramps on them, again we were very concerned that they were going to get low-floor potentially accessible buses but not put ramps on them.

That is when we were being supported, very much so, by the DDA Legal Service. Helen Finch was the advocate from the DDA Legal Service. A small group of us were meeting regularly about progressing this as a systems advocacy issue. It wasn't until after the protest that we discovered the order and our advocate at that time thought it was an excellent opportunity to apply for an interim injunction to the then Human Rights Commission. As you know, we were successful with that injunction.

The president of the Human Rights Commission, Sir Ronald Wilson, held a hearing in Adelaide, a preliminary hearing, about the injunction in September of 1994. That was to be followed up by a full hearing in October of that year, so a month later. Interestingly, just as an aside, that the preliminary hearing for the interim injunction was held in a courtroom here in Adelaide which was not accessible, so we had people outside and the media became quite interested in the fact that people couldn't get inside to the actual courtroom. The full hearing was set down for the next month - following the lodgment of our complaints. I don't think I really appreciated at the time just how much work was going to be needed by our advocate in the preparation of statements and information that we needed to have ready for the hearing.

There was a lot of attention on it particularly when, just prior to the hearing, the other states - Victoria, Queensland and New South Wales, and the Australian Bus and Coach Association and the Australian City Transit Association - applied to join the case as co-respondents. That was against three individuals with disabilities who were lodging the complaints. That, I must say, was a really stressful time. I can understand how the research by the National Children's and Youth Law Centre, together with the Human Rights Commission - when they investigated the number of complaints that had been lodged by parents of students with disabilities and found that the vast majority of people found the process very stressful, and they would find it difficult to actually use the DDA as a complaint again because of that reason.

The hearing commissioner, Sir Ronald, was wonderful in the way that he tried, as far as possible, to informalise the hearing, so that we didn't feel threatened by it all. But again my recollection of that week was one of feeling sick the whole week with stress. The end outcome and the conciliation that we were able to reach with the state government through that process was vital and really important. It set the foundation, I think, for ongoing consultation and involvement in the process of developing accessible transport here in South Australia - and influential elsewhere as well.

An example of that was when we were doing the design of buses here in Adelaide and looking at designs, it was suggested by an earlier steering committee that they build a mock-up of a bus, internal fittings of a bus out of timber, and then we got helped to facilitate a whole range of people with different disabilities actually coming down and trying to get onto it and working out the best way of doing that. We did that at a bus-building company here in Adelaide with those engineers. It was a really good learning experience for both the engineers - to see the range of people with disabilities on scooters and different sized manual and electric wheelchairs and looking at the access issues that were going to be faced by those people - but also the restrictions that they had with the Australian design rules et cetera for transport, and the restrictions of space, et cetera, they were going to be faced with in trying to do that.

MRS OWENS: Can I just ask, at that time were there no buses that could be bought off the shelf where all these things had been tested, say, in Europe?

MR CORCORAN: The general way that buses have been manufactured here for the local market is that more often than not the chassis is imported from overseas but then the construction of the body actually takes place - for the vast majority of buses - here in Australia. We have one major bus-building firm here in South Australia for the vast majority of the public transport buses here. The chassis are usually imported. The design plans et cetera, would be available - they were certainly available. There is also some commercial confidentiality about the way buses are actually designed and the costings, et cetera, which we found fairly difficult at the time we were trying to present a case, "Yes, this is feasible and it is not going to cost exorbitant amounts of money to actually make buses accessible" - which was the initial response and argument by those in power. The conciliated agreement and the agreement was that people would be involved in the development of accessible transport and that the state body, the Passenger Transport Board, would be very effective in the way they involved and engaged people with disability in that process. I probably just need to move on.

MS McKENZIE: You said you found the process of the complaint of the week before the hearing and the hearing - even though Sir Ronald Wilson tried to make it as informal as he could - stressful. Did you find the process of conciliation that followed, also very stressful?

MR CORCORAN: Yes. In many ways it was, and there were all sorts of external pressures as well. Leading up to the complaint there were people who were very critical of us; who thought that we were being quite outrageous in expecting all buses to be accessible. Some of that came from people within the disability sector. A lot of the pressures were that sense of responsibility because of the importance of the case. Again, it was my first experience of being in a hearing type of environment for the first time and not being exposed to being in a court system, et cetera, earlier on. Also it just added to probably my inexperience in that area. Does that answer your question?

MS McKENZIE: Yes, it does.

MR CORCORAN: I would just like to highlight some concerns: one was the courts authority here when the Magistrates Court had a major upgrade done. It had a heritage listing but there was a lot of work done to upgrade the courtroom. The way they ended up putting access in was to actually put a little platform lift just outside the building, so that if someone came in a wheelchair they had to push a button and wait for someone to come out and activate this little platform lift so they could get inside. It certainly wasn't access with dignity and amenity. The unfortunate thing was that the courts authority had done the right thing and consulted with someone who they thought would have the qualifications to advise them on what was good access. That wasn't the case.

We've had other cases here in South Australia where, for instance, the University of South Australia built brand new buildings on North Terrace and again they did the right thing in trying to get advice and again got very poor advice about what was acceptable. That led to major refurbishments having to be made just near the completion of the building which cost hundreds of thousands of dollars. It is just one thing I wanted to highlight: there are lots of renovations and building renovations happening all the time and the unfortunate thing is that quite often they're not using that opportunity to make buildings and internal fit-outs more accessible to people with disabilities.

I know there has been that gap between the Australian Building Code and the DDA and work has been going on to harmonise the Building Code of Australia with the Disability Discrimination Act through the Building Access Policy Committee but, in the meantime, there are thousands of buildings going up or being refurbished around the country and a lot of them are not being done using that opportunity to make them an accessible as they could be, and that's a concern.

MS McKENZIE: And it compounds the problem.

MR CORCORAN: Absolutely. Just another example which I think exemplifies attitudinal problems: it was interesting to hear the previous speaker mention that he thought attitudes were still a major issue. I know when I lodged a complaint against the Adelaide Entertainment Centre - because I wanted to go and see a show at the Adelaide Entertainment Centre with my wife and children and it was a Disney-type performance on ice - but when we arrived there we were shown to where the wheelchair space was going to be and we were told that only one carer could stay with me, so my wife was automatically assumed as a carer and the rest of the family had to sit elsewhere because there just wasn't the space for me to be able to sit with my family.

The person - who again was identified as a carer - actually had to sit behind me where my wheelchair was - they couldn't sit alongside of me. When we challenged that through a complaint the reaction was that we were being quite unreasonable to expect that my whole family should be able to sit together in one of those areas, because they just didn't have sufficient space they thought, for that.

MRS OWENS: But you went along to a family show with your family. Most other people can go to a family show with their family and sit with their family and enjoy it together. It's part of the experience.

MR CORCORAN: Yes, sure. But it was about, "You should just be grateful that you've got access. We've got a special place for you to sit " and that's it. That was one that went through conciliation - with a conciliator at HREOC - and we were able to successfully change their booking procedure through Bass and the publicity and promotion and general acceptance that you are able to sit with your family. They needed to address a whole range of things.

MRS OWENS: Did they reconfigure the spaces there?

MR CORCORAN: Yes, they did. They did a lot of work in actually promoting it to their patrons about how better to accommodate the needs of people with disability, so it was a really good example to me. We met with the conciliator at the Entertainment Centre and went through some fairly clear steps of how they could address issues in the future. It was something that was certainly agreed to and went forward and I think that's a really good example of the DDA being used just at a local level.

MS McKENZIE: Did you put your claim as direct or indirect discrimination or both?

MR CORCORAN: I think I did it as both direct and indirect because of the response we got from the person on the night who was ushering us there and saying, "Well, I think you're being quite unreasonable to expect - - -"

MS McKENZIE: "You've got access. Why expect more?"

MR CORCORAN: Yes. "You've got access, you just don't need to sit together." Kendell Airlines was another case I was involved in. I had made a booking. I had to go to Whyalla to run, funnily enough, some Train the Trainer programs for TAFE lecturers on advocacy and the training modules we had developed. I received a phone call from the local general manager at Kendell Airlines that night on my mobile phone while we were at dinner to say, "We've made a terrible mistake, Mr Corcoran. We weren't meant to fly you there. We have a policy which says we can't fly people in wheelchairs unless they can get themselves into the plane on their own." I thought it was quite - - -

MRS OWENS: Can I ask how you were going to do that? Were you going to sort of crawl up and drag the wheelchair behind you? How were you going to get into the plane by yourself?

MR CORCORAN: They actually had a description in their policy of describing a person who is a paraplegic, bumming their way up the steps into the plane and they described it as "shuffling on their bottom up the steps onto the plane" - that was acceptable. They actually had that within their policy. They were actually silly enough to send me their policy at that time. My response at the time - because we had pretty well finished working on the transport standards at that time - was, "Were they aware of their obligations in providing public transport?"

I suggested that I would be at the airport the following day and I would be expecting to fly and, if something happened and I wasn't able to get onto the plane, I was going to make arrangements with the local television station and media about that. I didn't sleep much that night - - -

MS McKENZIE: More stress.

MR CORCORAN: - - - wondering whether I would be able to get the plane the next day. When I got to the airport I was met and greeted by the pilot who escorted me out to the plane and they had actually changed it to one of their larger planes. The issue for me was that if I am travelling by plane I have to transfer out of my normal wheelchair into a smaller aisle wheelchair, which fits down the aisle of the plane. The plane going up there didn't have any raisable arms on the seats - so that you can raise the arms over and transfer across - but as a quadriplegic I don't have the arm strength to be able to lift over those arms so I had to rely on people lifting me to go up. On the way back - because they had the arm raisers - I could transfer over.

I ended up lodging a complaint because there was another trip where they insisted - I had to go to another country area as part of my work - they would only carry me if I arranged to have, in their words "carers at either end" to put me on and take me off the plane. They wouldn't fly me from Mount Gambier back to Adelaide until I could actually confirm who those people were who would be meeting me at Adelaide Airport to get me off the plane.

The reason I wanted to use this example is because I contacted a law firm about the case because I wanted to ensure we had good representation on this. We actually got a fairly well-known lawyer who had a law firm here in Adelaide - who also happens to be a quadriplegic - and he helped take statements and prepare information from witnesses and other people, et cetera, for the case. But when we came to the first attempt at a conciliation hearing with HREOC, they came with their lawyers from Kendell Airlines - I think there were two lawyers from Kendells and Ansett Airlines also had another two or three lawyers who came along as well - who flew in for this meeting. My advocate and legal person wasn't advised that the other lawyers would be coming from Ansett for the hearing, because they - there were obvious connections between Ansett and Kendell Airlines.

MRS OWENS: No wonder Ansett went broke.

MR CORCORAN: Yes. That was interesting because my lawyer Paul - I'll call him by his first name - said, "Who are all these other people?" The conciliator said, "Sorry, we didn't have much notice on this. These are the other lawyers. Do you mind them actually joining in with this conference?" He said, "I think I do actually." These other people had lawyers who had flown - I had to sit outside in a room while we attempted to work through a process about trying to resolve the matter.

The difficulty for Kendell Airlines, certainly with some of their smaller planes, is that where the roof doesn't allow someone to stand up straight within the plane, then they are unable to actually do a safe lift or help assist with the transferring of a person with a disability into their seat. They also had their own duty of care towards their employees and the occ health and safety issues that they needed to address. Again, it was one that I knew they were going to actually challenge all the way and it was one that came into play following the cost jurisdiction issue. If I wanted to enforce my position I would have to take a risk if costs were awarded against myself.

But there was also an attempt by the conciliator to say, "For a period of time can we just take the lawyers out of the room and have some discussion initially about progressing this further?" - which I did. Again, I found that process really quite stressful. The legal firm had done a lot of work for and on behalf of my case and we had some agreement that Kendell would go away and do a whole lot of work around looking at access into their planes and work, again, with us on ways to actually do that, which we did and they ended up buying equipment to have - like a miniature forklift in all their airports to actually raise people up to get into some of their larger planes.

It's a worldwide problem. There are so many people isolated in regional and country Australia who can't get on a coach or can't get on a small aircraft. It's only small aircraft that are servicing those areas now, so if they need to get to Adelaide, they need to get to a capital city for treatment, or if someone dies and they need to get there really quickly, it's a major issue. Later on, Kendell Airlines were able to successfully get an exemption under the DDA for this particular area, on the basis that they develop a disability action plan. Regional Airlines of Australia also applied for an exemption, but their application was very disappointing and I think it was knocked back on that basis.

Just as recently as early this week, I've had discussions with the Human Rights and Equal Opportunity Commission, again about this issue, to see whether there is any further work and research going into a technical solution to allow the easier transfer of a person from a chair into a seat, whether it be by a light little hoist that can be fitted up or some other means, but at the moment we have people all around Australia who can't access aircraft travel.

MS McKENZIE: It's not a problem in the States? There are not perhaps so remote areas, but there are very big areas to cover and quite small towns to go to. Has this not been raised in the States?

MR CORCORAN: Yes, it has. It is an issue in terms of access there. Communication with the University of Pittsburgh again this week has confirmed that there is not a lot of work that is happening in that area. If we can put people on the moon and do all of those sort of things, we should be able to get a person in a wheelchair into a light plane some way. I just think there is not the emphasis on technical solutions and resources being put into looking at technical solutions, for some of these access areas. Again, it needs to do that.

I've brought along some work as examples of what the University of Pittsburgh and the National Institute of Rehab in America - they are actually doing a lot of applied research about the safe carriage of people with mobility devices in public transport. That is important work that is actually happening, but it's not well known even here in Australia about what is happening over there. It's only a small group or number of people who know about that.

I had better move on, I'm dragging a bit. I have currently got a new complaint at the moment with the Commonwealth Bank, in that they have closed down a lot of branches around Australia - including my local branch at Semaphore - which was very accessible. I could wheel in and out and get into it. The bank which is right alongside the office where I work here in the city has got two steps into it. It has been like that now since I started work. I asked them about doing something about that over 18 months ago. People in wheelchairs and frail people, who are worried about using those steps, still sit outside the doors of the Commonwealth Bank in the mall to be served and they come out and serve us. We are waiting on a response from the Commonwealth Bank.

MRS OWENS: Can't they afford a ramp?

MR CORCORAN: I don't know whether they can. They are only making about a billion dollars every six months.

MS McKENZIE: It doesn't have to be gold-plated.

MR CORCORAN: No, I just want to be able to get in there. Initially there were all sorts of reasons given: you know, it was in the plans and it was going to happen. That was 18 months.

MRS OWENS: But it's not just you, Maurice, that wants to get in. It's every person that has got a pram; it's elderly people who may not want to climb up stairs after they've had a hip replacement.

MR CORCORAN: Absolutely.

MRS OWENS: There's all sorts of people want to get into their bank. You know, the people's bank. So you've got another complaint going?

MR CORCORAN: Yes, that's happening at the moment.

MRS OWENS: You are going to go through all the stresses of another complaint?

MR CORCORAN: Yes. I wrote to them and communicated to them well over 12 months ago - probably 14 months ago - about doing something about it and they still haven't done anything about it. I think the time has passed - one day I got particularly frustrated when I had to sit out there for ages.

MRS OWENS: We're not here to listen to your complaint, obviously, because we're doing an inquiry to the DDA, and HREOC can do this far better than us, but has the Commonwealth Bank explained to you why they haven't addressed this problem?

MR CORCORAN: They have just sought an extension through HREOC to their response from my complaint. We are hoping to get that response within the next month or so.

MRS OWENS: We will follow this as it goes through. It will be a very interesting one for us to use as a case study perhaps.

MR CORCORAN: Yes, I would be delighted.

MRS OWENS: Except if they keep on asking for extensions it might be too late. We're reporting next April. Let's see what happens between now and April.

MR CORCORAN: Yes, that's true. I wanted to skip through some of the other areas. I will move to my fourth area. Unlike the previous speaker I was fortunate fairly early on, when HREOC ran some really useful workshops here in Adelaide along with the DDA legal advocate on how to use the DDA, the user guide to using the Disability Discrimination Act and the information that was circulated pretty broadly - I thought has always been very useful. There is, unfortunately, a risk to the sector at times if people do lodge complaints, and are doing it in isolation and may not have the actual support around them that they need, particularly if they are going to be setting precedents for agreements that can be reached - there is always a bit of a risk with that.

The deterrent about the costs and the decision - that enforceable decisions could only be made in the Federal Court - has had a really detrimental effect on people lodging complaints and feeling okay about following that through. Anyone -like the Commonwealth Bank for instance - can just say to me, "Not interested in conciliating with this issue. We will get to it when we get to it. If you really want to take us on we will see you in court." They could actually do that if they wanted to. I'm not sure how confident I would be - although it's pretty black and white - but there would be a big risk associated with going through the Federal Court just knowing that and having it hanging over you.

I just want to touch a little bit on my experience as a paid advocate as well. The DDA, in many respects, has been a really useful piece of legislation. Even when you don't have to use it, it is there and for those people who want to do the right thing and don't want to be embarrassed by a complaint, or who become aware that someone might lodge a complaint, therefore are far more willing to come to the table and discuss issues and try and resolve them so that it actually prevents a complaint being lodged. That has been a really useful and very powerful tool, just having that as an advocate and raising the awareness of whoever the respondent may be.

The awareness raising and training is crucial to organisations not discriminating. Certainly the disability action plans process, we grasped - when I was at Disability Action I actually made one of the positions into a disability action plan project worker. That person, Jill Fowler, who was in that position, did a lot of work with local governments, holding conferences on how to do disability action plans, the sort of things that could be addressed, and the importance of disability awareness training. That led to us actually doing some consolidated consultancy work for the five larger councils here in metropolitan Adelaide, where we did a training needs analysis for them on disability awareness and discrimination.

Dr Elizabeth Jardine was working with us at the time to do that analysis for them and that became the basis of them identifying within their action plans different components of disability awareness and training that, for instance, an engineer would need to do, so that they are familiar with the access standards and the technical requirements. But what would a librarian need to do? What would an elected member; what sort of level of disability awareness? It's really set up the training and components based on different roles and expectations of staff within local government. Then the local government have gone even a step further now and developed that into a very good training package which is on CD-ROM for local governments. That was launched earlier this year. They're going to be implementing that training now across local government.

MRS OWENS: And that's across local government across Australia.

MR CORCORAN: Certainly in South Australia.

MS McKENZIE: Or just in South Australia.

MR CORCORAN: Yes. But it's available. The CD-ROM will be available from Salisbury Council for any local government around Australia. Again, it's tailored towards local government and the things they need to do.

MRS OWENS: Have you got any comment you'd like to make about the outcomes, in terms of what has happened within those five councils in terms of their approach to people with disabilities now? Have things improved?

MR CORCORAN: I certainly believe they have, in those areas that have been looking critically at access, and if I just use Salisbury City Council, who have contracted a person full-time there now, Mike Taggart, who has a role in overseeing and managing a committee, which is their disability access committee, across local governments and I think a lot of local governments have got their own disability access committees now and do a fair amount of work on that. I think that's been really useful in terms of their being willing to actually move down that way and be proactive. But I do question the fact that in the action plans they're not mandatory.

MRS OWENS: Would you like them to be?

MR CORCORAN: I certainly think that with three levels of government that could be something that is done more regularly. It is a proactive way of doing it where both state and local governments have moved down that line to address lines and to develop disability action plans. It has to raise awareness and it does seem - although it's a long process it is certainly better than it was back before actually doing a lot of that work, I think.

MRS OWENS: But now that there is, as you say, CD-ROMs and so on, for those that follow there are probably very good examples of how to do it, so the process is future may not be as difficult or as lengthy.

MR CORCORAN: I agree, but I guess the thing that I try and promote and encourage first and foremost is that there are a number of organisations who still have the mentality of being able to give the job to someone in the human resource area to go away and write up a disability action plan.

MRS OWENS: And a bit of paper compliance.

MR CORCORAN: Yes. Really, you can't do any of that, I believe, without good disability awareness and discrimination training with those key people who have involvement with the disability action plan. They are not going to identify what the barriers are, they're not even going to identify what the access needs are, until they've actually done that disability awareness training. I think that's just so critical - as a first point - to do it with those directly involved with the disability action plan before they go too far down the line.

MRS OWENS: I think our previous participant made another very useful point which was that you really need this driven right from the top, and not just necessarily sidelined to somebody more junior; to own the process you really need it up at the board level, the chief executive.

MR CORCORAN: I guess one of the things we've tried to do, to actually promote that happening, is to highlight the vicarious liability part of the act and that if under - for some reason - a member of staff or someone within local government does discriminate, either directly or indirectly, and during the investigation of that complaint it's discovered that there has been no provision of staff training in disability awareness, that the complainant could potentially - again, lodge the complaint against the CEO or the elected members for not implementing proper training in that area. I think that's something we've just got to continue working on, because of juggling priorities, et cetera - the elected members and directors and executive directors have.

MRS OWENS: What about the private sector? Introducing action plans, making that mandatory - you've talked about through local government, but what about the rest of the economy? The Commonwealth Bank?

MR CORCORAN: Yes. Wouldn't that be lovely?

MRS OWENS: They may have one, I don't know.

MR CORCORAN: Yes, they probably do.

MRS OWENS: If they have, that would be nice to know, wouldn't it?

MR CORCORAN: I guess that's the thing. If, on the ground - a lot of these large companies can develop a disability action plan, but if it is not transferred to more inclusive and accessible services on the ground then it's - - -

MS McKENZIE: Paper compliance is a matter that has been raised with us.

MR CORCORAN: Yes. If you are going to make them mandatory then there have to be the associated resources attached to monitor those plans to ensure that they are compliant and they do make changes on the ground. Can I just move quickly on to - not quickly - move on to the area of standards development. One of my greatest frustrations, being involved in the transport standards development from the end of 94 onwards, was the constant struggle to get enough resources to support the consumer process as far as what should be happening. I know all the work done by the consumer representatives were on a voluntary level and so you are sitting around tables constantly with people on considerable salaries and resources and backup and the same expectations on responding to drafts, responding to comments or tasks to further develop standards.

It had been incredibly demanding on the people who were actually involved in that. Holidays, weekends, night-times, et cetera, over long periods of time were taken up with work doing that. I'm not begrudging that, but I just think if we're serious about developing national standards, the allocation of $120,000 for the entire DDA standards project which was to pay for a coordinator, a national coordinator to run an office and to support all the consumer representatives who were on developing the standards, was fraught with difficulty.

MRS OWENS: I think that's an understatement.

MR CORCORAN: As the national coordinator of the DDA standards project for two years, I left Disability Action in 1999 originally on secondment to take up that position, and we were able to backfill the executive director role at Disability Action for a period of time until I later resigned. But it's not only the lack of resources but the funding - the two-year funding agreement. One year had expired by three months and the project had to continue its work unfunded.

MS McKENZIE: Unfunded.

MR CORCORAN: It was just fortunate at that time that we were auspiced by Blind Citizens of Australia and so I reported to Blind Citizens of Australia. They had sufficient resources at that time to be able to continue to pay my salary and to cover basic expenses. But you couldn't plan anything in advance and yet we were expected to be consulting with the community nationally on a range of things.

MS McKENZIE: It's ridiculous that the ongoing funding of such an important project should be left to the goodwill of one particular organisation of people with disabilities.

MR CORCORAN: Yes. I guess, also, if you were really going to look at the support and the development of the standards, that's a good indication of why they took so long to develop, which is a major criticism of the transport standards - the length of time that was involved in developing them. At the end of the day, we had people who were always questioned about the need to stay over, when you were flying interstate for a meeting. There was fairly detailed questioning about a lot of the expenses that the people on the other side of the table never had to do, anywhere near as much.

So I'd get to the situation where we'd be flying in and out on the one day, rather than having a motel accommodation bill, in order to actually support representatives who were working in the other areas, like the building codes, et cetera. Yes, it was problematical. Obviously justice department - in attorney-general's which funds the DDA standards project - were under their own financial constraints, et cetera, but we actually had to really advocate and, in the end, actually get that funding continued and paid back to the organisation. That was a real concern.

The other thing that I guess helped us is that the people who were involved had the passion and the commitment to try and see it through and I think we were really fortunate with that, with the key people who were involved in that, and lots of support from outside. But one of the things, again, that needs further discussion about resourcing was doing the regulatory impact statements, where industries like the Australian Bus and Coach Association could spend 4 or 5 hundred thousand dollars on consultants to use and develop their arguments about the cost implications of the DDA standards and what that would mean, and how it was going to send them broke within 12 months, if they had to comply with those standards and didn't get funding.

We had to, again, rely on volunteers to develop the benefit argument, the other side of it, and we were very fortunate to get people like Peter Vintila from Perth and Jack Frisch, an economist from New South Wales, who committed lots of voluntary time for us, challenging some of the economic modelling that the industry was putting forward and the assumptions behind those economic models, which really did need to be challenged. Then the risk process was that the consultants who were contracted to do the work on the regulatory impact statement, Booz-Allen, at the time - they were transport consultants and so they had an interest in - I'm not saying they had a conflict of interest, but it was very difficult for them, I think, to have as much experience or knowledge from the disability sector perspective and the cost to people with disabilities of not having accessible transport and also the benefits of not doing that. We argued really strongly that Peter Vintila, from Perth, be included within that risk consultancy program; that he became a sort of a subcontract of Booz-Allen, but he is someone who - - -

MS McKENZIE: Almost like an independent expert.

MR CORCORAN: Yes. But he felt and remains really angry about the way that his work was used by consultants and he may - I don't know whether Peter is going to submit anything to the Productivity Commission, but he was very concerned about the way his work was misinterpreted and undermined, he thought, through that process.

It's something that again we're going through with the education standards. Fortunately it's been very reassuring to read the latest consultants' report - who have been looking at the education standards. They seem to have got a much better grasp on the potential benefits and effects for people with disabilities. I really do think that, because of the regulatory legislation side of it and under the COAG agreement, that a risk must be developed, we really do have to look at how we can support the disability sector side of the argument about developing the benefits side of that.

MRS OWENS: Can I just clarify something? Who was responsible for employing Booz-Allen?

MR CORCORAN: There was a small steering committee of the accessible transport task force, but ultimately the contract was with the attorney-general's department, justice.

MRS OWENS: They presumably would have let it out to tender?

MR CORCORAN: Yes, I was involved in the committee and it did go to tender and went through that process, yes.

MRS OWENS: This sort of work really needs to be done by people with economic training. I'm not sure whether any of the people that would have been involved at Booz-Allen had that sort of training or not. I've had quite a lot to do with Booz-Allen in other contexts and I've seen them do some extremely good work, but it's been in relation to very traditional costing approaches, what I would call accounting costing approaches. What we're talking about here is looking at it in a far broader way, the way that we look at doing such measurements for the commission from a community-wide focus, looking at the broader benefits, measuring the costs for particular groups in society. Booz-Allen is not here to clarify this but I wonder about what the brief looked like and the criteria for selection in that case. We won't go into that now. It's probably going beyond where we should be going.

MR CORCORAN: We liaised really closely with the Office of Regulatory Review on some of those things but at that time the level of sophistication of some of the (indistinct) was not all that terrific. It didn't seem to be anyway from the examples that we saw. Some of the arguments that were being put forward by the transport industry was the fact that they're going to lose anything from three to five seats because of the wheelchair spaces on buses, even though we always said put flip-down seats in there - and they did do that - they costed they were going to have to increase their fleet by 15 to 20 per cent to make up for that shortfall and the costings and everything that went in to do that and the maintenance that went in to do that over the years. But, yes, I just wanted to flag that as a concern.

Also the training and the research funding: one of the things about transport that we've always said is that all of a sudden when we're getting more and more accessible transport that we just expect people with disabilities will know how to use it. In America and the UK they've actually had concerted training programs, quite often involving people with disability who are doing the training, but just taking people through some transport training and giving them the opportunity to trial getting on and off a bus when it's not on a fixed route and people are not staring at them or glaring at them because it's holding them up and they're not in their wheelchair spaces as quickly as they should be. There needs to be, and we continue to argue for that - we think there need to be more opportunities for that to actually happen.

Lastly, just on the transport stand are that safety issues continue to be a major concern for myself. We do have people who are - in terms of people who are using scooters, taxis et cetera. In taxis there's been some risks associated with that. Also, again, the safety issues in light aircraft, et cetera. With the increasing number of people who are now starting to use public transport, the safety aspects have to be taken into consideration. I know the rail crossing issue hopefully would have been brought up with the commission, and it's a major concern not only here but in America where they have an average of one a week die as a result of being trapped on the lines. It is a major concern. I think I'd better stop there.

MRS OWENS: You had a video to show.

MR CORCORAN: Yes.

MRS OWENS: How long does that take?

MR CORCORAN: It takes about 12 minutes. It's about a 12-minute video.

MRS OWENS: It's just before 1.00. I think we could do that.

MS McKENZIE: Yes, we can. Why not? Of course we can.

MR CORCORAN: I think it's a positive way to - - -

MRS OWENS: The transcript can't see a video, but we can - it's got sound?

MR CORCORAN: It's got sound and it's got captioning.

MRS OWENS: We can record it. I might just move over a little bit. If there are any questions, you'll have to ask them because I won't be near a microphone. We can probably get a copy.

MR CORCORAN: The video is actually marketed through Film Australia.

MRS OWENS: We can get the details of the video and we can track it down later.

(Videotape played)

MRS OWENS: Thank you for that. We enjoyed that.

MR CORCORAN: I'm sorry, I've taken you way over time.

MRS OWENS: We didn't get around to the hard copy of your slides. You've covered the issues in those slides, haven't you?

MR CORCORAN: Yes, I think so, as much as I can at this stage. Yes, I think we've gone as far as we can.

MS McKENZIE: That was a very comprehensive and interesting submission. You covered lots of issues.

MR CORCORAN: Thank you.

MRS OWENS: I think we have covered most of the questions we wanted to ask you as we've been going. It was, as Cate said, a very comprehensive submission and I think, Maurice, you should be really proud of what you've achieved. Just looking at that video - - -

MS McKENZIE: Not just for you, but for all sorts of people.

MRS OWENS: For all sorts of people, and the two others that went through with you on that initial complaint. It's a wonderful outcome. We're not there yet, but we're a good way along the road.

MR CORCORAN: Yes.

MS McKENZIE: Not only that, but you're not deterred from doing it again. Given what you said, you could easily - - -

MR CORCORAN: We've been lucky enough to be, in some ways, the people who've had the direct involvement and that's been a wonderful experience as well. It's been a very positive experience, as well as all the frustrations, but there have been lots and lots of people right around the country who have been busy - you know, doing the submissions and responding and going to forums and stuff like that - who all need to be acknowledged through the process as well.

MRS OWENS: Thank you very much. We'll now break for lunch and we'll resume at 1.35.

(Luncheon adjournment)

MRS OWENS: The next participant this afternoon is the Australian Association of Special Education, South Australian chapter. Welcome each of you. Would you like to each give your name and your position with the association for the transcript?

MS LYNCH: I'm Margaret Lynch and I'm the vice-president.

MS McMULLAN: I'm Jeanette McMullan. I'm a committee member on AASE and I have the responsibility of managing the professional development of AASE members.

MS ALDERTON: I'm Ingrid Alderton, a committee member on AASE, and participating in the newsletter and professional development committees.

MRS OWENS: Thank you, and thank you so much for your submission. You've just given me an annotated version today, so thank you for that. I understand that you'll run through some of the points in the annotated version, but I'll hand over to Margaret. You were going to make a few introductory comments and then hand over to Jeanette.

MS LYNCH: Yes, that's right. The Australian Association of Special Education is a research based non-categorical organisation that advocates for the provision of quality educational programs for students with special needs. Its membership comprises teachers, educational administrators, therapists, university researchers and parents. Members of AASE are from government and non-government education systems and we believe that the submission that we're presenting represents the views of both the government and non-government members of our committee. Jeanette is actually going to talk some more about our submission and expand on some of the points we made.

MS McMULLAN: Thank you very much, Margaret. We had another look at our submission the other evening and wondered: what were the most important things we wanted to bring to your attention from our submission today? I've summarised those under five major themes. I'll list the five headings and then maybe I'll move into a bit of discussion and possible questions from people on those. The five major themes that we highlighted were enrolment, attendance at school and the curriculum design and delivery. That's one - the issue of enrolment, attendance, curriculum design and delivery.

The second issue for us was access to post-school services that support students' transition from school to work, further study or life in the community. The third one we highlighted was the obligation of competing legislation, particularly the Occupational Health and Safety Act and the DDA. The fourth one was inconsistent funding and support arrangements available for people with disabilities. The fifth one was the increased negotiation and documentation, whether it's individual education plans or NEPs, as we call them in our state. They were the five major points that we have some concern about.

If I go and look at enrolment, attendance at school and the curriculum design and delivery, the biggest impact on pre-schools and schools, as well as the services that go to those schools and the agencies that go to those schools, is on the time required. It's the time component that's required for releasing staff for planning - so if you're going from a pre-school to a school or from a school to another site - the conducting of assessments; the supporting transitionary arrangements from one site to another site; the finding of employees to support students or training staff; the waiting for decisions to be made by any of the services, agencies or school sites; and - the one that impacts significantly on teachers at the schoolface and in the classrooms - the designing of a curriculum delivery approach to include and to accommodate the students' needs. I wonder whether Ingrid or Margaret want to give any examples or talk to any of those points.

MS LYNCH: The one about waiting for decisions to be made - just over the last two weeks I've had a classic example of that, where a mother moved to Adelaide with her seven-year-old son with autism and intellectual disability. Her son was in a special school in another state. She went to the local primary school, where she knew there was a special class - it wasn't a special school, but she knew it was a special class - and assumed she would be able to start her son at that school. We have processes that are followed for entry to special classes in our state and so I had to talk through the need to gather assessment information. It goes to other people; school psychologists, et cetera.

At the same time as talking to this mother, I realised that she didn't have any other supports in the state, so I spoke to her about accessing the Intellectual Disability Services Council and I undertook to get some information to connect her with that family support. That took probably seven or eight days to do so. When I finally made contact again, mum was feeling very frustrated with not - in the meantime, I had rung the mother and said, "Look, it's at this stage," and IDSC had made contact, but it was her hope that she would be fully supported once she arrived here and, because of the way we work, that wasn't possible. On Wednesday I got a phone call to say, "I'm thinking of moving back to Queensland," even though we'd hoped to have the child in a school after our next two weeks of school holidays, and yesterday I got a phone call to say she'd gone back.

MRS OWENS: Has she gone back because of these barriers?

MS LYNCH: Yes. The conversation on Wednesday was around what she perceived was the lack of support that was available to her in her situation.

MS McKENZIE: It's very unfortunate for the mother, the child and - - -

MS LYNCH: Yes, quite distressing, I would imagine.

MRS OWENS: I just wonder how much better things are in Queensland. She obviously had found it was a more responsive system.

MS LYNCH: Yes. In previous phone conversations, I had the feeling that she had received quite a bit of respite and felt fully supported. What the circumstances were that prompted her move to Adelaide I don't know, and I'm wondering if there had been some personal trauma in some way and she came down here, perhaps not having thought through that there might be a different system in this state for accessing services, and was in a vulnerable situation herself anyway.

MRS OWENS: It raises a broader issue about the quality of treatment of people across Australia - - -

MS LYNCH: Yes, and that's one of the other issues that we - - -

MRS OWENS: - - - when you have different systems in place.

MS LYNCH: That's right.

MS McMULLAN: That sits under the inconsistent funding and support arrangements as well. The waiting one is a typical thing that happens. We've had a young person for 18 months - we've known he was coming from New South Wales - and I've not been able to say to the parent, "This is the school you'll go to," because it's about vacancies within our system and whether there are vacancies that exist or don't exist, and you don't know until you're almost here whether there is a vacancy available or not available. You can't hold a vacancy within our system, because schools are funded for people attending. You've got to have eight students, for example, to buy a teacher. It's difficult to hold vacancies knowing someone is coming, so waiting is problematic.

On that first issue, I suppose I wanted to highlight the impact that is along the way of every aspect of a young person's life. From the time they enrol, there will be issues that need to be addressed and a lot of service providers work very hard to address these issues - and do it very well - supportively of families. It takes time, it takes coordination, it takes collaboration, it takes planning and it happens and, hopefully, most of the time it happens smoothly, but all those things need to happen. You can't just lob in and think it's going to just work for you, because it doesn't work that easily. The one that we haven't emphasised in this is the designing of the curriculum delivery approach and that, for the class teacher - who is probably the end of the line, obviously, for the child - is a big issue and needs a lot of support and also a lot of expertise to be able to do that.

MS LYNCH: I'd just like to elaborate a little bit more there. In South Australia - and I think it's the same right around Australia - the age of the teaching force is heading towards retirement and, when we were trained, we didn't have to consider these students in our classes. It becomes a huge challenge to teachers to actually reflect on their practice and, you know, adopt more inclusive strategies than what was perhaps part of their usual teaching style, and that can set up tensions as well.

MS ALDERTON: Certainly, in relation to pre-service training for teachers, there is a significant issue in terms of special education knowledge and also catering for students with learning difficulties and learning disabilities. Anecdotally, we have a lot of information from pre-service teachers, but it's insufficient. Certainly, Mapping the Territory - one of the DETYA projects - emphasises very much that's an issue.

MRS OWENS: What's that project?

MS ALDERTON: Mapping the Territory looked at the support for children - students - who have learning disabilities and learning difficulties. I think it was about 1999, and it indicated the significant need for more effective pre-service training of teachers, as well as on-the-job training - that timely training.

MS McMULLAN: Moving onto the second issue that we wanted to raise - was access to post-school services that support the students' transition from school to work, further study or life in the community. We have a number of issues in relation to that and, from our perspective, it's sometimes about good luck rather than anything that's planned or anything that's transparent or anything that's accountable. It's not there. We talked about Centrelink. We talked about the ability of families to receive disability support funding. We've had many examples of where it's based on the letter that was written by the medical practitioner and how that's given.

We've had a huge issue with Centrelink making decisions based on the "what" score, rather than looking at the design of the form and the functional information that is given to finding people necessary places with job centres. I believe that that's being reviewed in parts of our state and, certainly, we're getting better at looking at the information - and involving schools in providing that information as well - so that we can try and do that in a much better way.

One of the typical examples that we've had with case management approaches is that the, say, career systems which one of the case management agencies that I know will have - not knowing how many vacancies they've got to have a young person into one of their career pathways and suddenly they will have and they will ring up a school they know well and say, "Have you got any students that are interested?" It just seems to be hit and miss, and that's not a reflection necessarily on those systems. They're not guaranteed of how long they're going to be in existence or how many places they will have to fund, so there are waiting lists for young people there.

We have a new strategy in South Australia called Futures Connect and we're hoping that will assist young people with disabilities, but we haven't heard any more than that. They're having transition brokers for all young people and schools were hoping that they'd focus on students with disabilities as well, so we're hopeful, but we are also very concerned about pathways beyond school. I have a couple of examples that I'd like to share, and I put them into the annotated version, which I do notice has got references to the page numbers at the beginning. But I come from the north of Adelaide, as in my job, and we've been doing post-school destination mapping for two years and out of students with disabilities 61 per cent did not have outcomes that led to employment or further training; 61 per cent of the students with disabilities that we had in our schools did not lead to that.

MRS OWENS: Do you know whether that's getting better or worse? It sounds like a very large proportion. But is it something - - -

MS McMULLAN: I can't - I don't have it here.

MRS OWENS: We haven't got any trend data.

MS McMULLAN: Don't have any data to do that.

MRS OWENS: It's only two years.

MS McMULLAN: Two years, and it's only been two years we've been able to do any kind of tracking.

MS LYNCH: Perhaps can I just say there, this Futures Connect strategy that Jeanette mentioned is aimed at addressing that, so that all students in secondary schools, including students with disabilities, will have a pathway mapped out - you know, starting in year 8 right through - and then even when they leave school there is a system being put in place to track what happens to them.

MRS OWENS: And at least be able to get into some training to do something.

MS LYNCH: Yes.

MRS OWENS: If not into employment immediately. The idea that 61 per cent don't go into employment or further training, it seems like a remarkably high figure. That's why I was asking about - is this getting better or worse, because I don't know which - maybe it used to be 80 per cent.

MS McMULLAN: No, we don't know. We have just a couple of points I'd like to put further to that and then I think I'm quite happy to leave that topic. The example I have is that one of our staff members has a young daughter with disabilities. She has done many course. She has done a waitressing course, she has done a fish course - for filleting fish, or whatever they do at one of the TAFEs - I think she has done five courses. She still does not have any employment that is guaranteed; it's all like 10 hours here some weeks, none the next week, 15 the next - "Oh, we've got full-time that week." It's in a variety of things. So she's done lots of different courses but she has got nothing where she can say - even permanently employed, or part-time employed or get 10 hours a week. There is no consistency of her employment there.

I've made reference here to Para West re-entry. Para West re-entry for us is a senior secondary school which takes adults who have left school. We've got about four maybe in our state. So some of these young people - my data will show that 14 per cent were, by their job agencies, redirected to Para West re-entry. That's probably not an appropriate redirection, because that's about adults going back to complete certificates so they can go on to further qualifications at TAFE and universities. It's not meant for people with disabilities in the - I suppose it could be for some groups of people with disabilities - I'm sorry about that. But in the main the ones who are being redirected - there are students with intellectual disability and it's probably not appropriate to redirect for them.

MS McKENZIE: But are the agencies referring these people back because there is some lack - - -

MS McMULLAN: For increased literacy skills or increased functional skills, yes.

MS McKENZIE: So it's because of some gap that they've identified that needs to be - - -

MS McMULLAN: Yes, they are, and as an educator in special education for people with an intellectual disability, where you're working with adults who are going to increase their literacy skills because they want to go and get their SACE or their entry into university - they are two different purposes for the courses. The third one is the obligations of competing legislation.

MRS OWENS: Just before you go on with that, you say that 20 per cent did result in employment, coming back to this data.

MS McMULLAN: Yes.

MRS OWENS: What sort of jobs? Any idea?

MS McMULLAN: No, not - I would have some back in my office, but it - - -

MRS OWENS: But they might be part-time, they could be casual.

MS McMULLAN: And we don't know whether they have stayed there. We don't know whether they have stayed there.

MRS OWENS: Levels of retention, yes.

MS McMULLAN: Yes. Again, this is anecdotal evidence, and this is our local. We had a large international body of people come to talk about - north is probably in a fair poverty area of our state - employment and post-school options for people with - all people there. Even with the industries there, industries were quoted as saying, "Well, if they live in Elizabeth we don't really want them on our site working." So that's been recorded publicly in one of our local newspapers and quoted. So it's difficult. Any more questions?

MRS OWENS: :You were coming up to number 3.

MS McMULLAN: This one is really about catering for young people with disabilities in classrooms and teachers and administration staff and other school staff who feel threatened because of the violent and unpredictable behaviours of young people with disabilities. Their workplace is unsafe. They feel they cannot provide a duty of care to other students, resulting in suspensions and inclusions of students and also the increased difficulties that places on parents who have young people with disabilities, not at school because they have been excluded, or we can't find appropriate alternative placements for them.

A lot of good stuff happens. I don't want to sound all negative, because a lot of good stuff does happen in terms of how we coordinate specialist options and solutions for them, but again, that takes time and it takes processes that we've called here wraparound approaches, in order to make that work for young people. It's really about the time it takes and it's about the impact that has on staff. We have schools that will say they don't want particular children. At the moment I have three young people not at school because I cannot find a school or a place or anywhere for them to attend.

MRS OWENS: Because of the occupational health and safety issues or safe - - -

MS McMULLAN: Yes, because of their violent and unpredictable behaviour. With all the alternate solutions we've tried, we've had them in, and there are no vacancies for them to go back into them, and there's nowhere for them to go.

MS McKENZIE: So do they just stay at home?

MS McMULLAN: They stay home, yes.

MS McKENZIE: And they do nothing.

MS McMULLAN: I went to a meeting - my example, I know I'm hogging the floor here, sorry. I went to a meeting yesterday for one young person. It was called a management assessment panel meeting, which is an agency that has looked at the most difficult young people we have in our system within South Australia, and problem solving - so you have on there very highly skilled psychiatrists and medical professional people and psychologists and reps from loads of agencies. They bring all the agencies together, so they will bring FAYS, the Family and Youth Health Services or IDSC, Autism Association - they will bring them all together - university people. They bring them all together to problem-solve.

At this meeting yesterday for this young person, the young person stormed out of the meeting. He trashed wards in the building where this meeting occurred and ran away. He has not been at school this year. We are not looking at a schooling option for him now. He is 15 and we are going to see how we can do other things for him, because we just cannot find him a site. I have another young girl who ended up in Magill Detention Centre because she had violently abused her father, who had cancer - because we have not been able to get her at school all year. I can give you more examples and I am sure my colleagues can, too.

MRS OWENS: It's incredibly difficult for these kids and for their parents - - -

MS McMULLAN: The parents are losing paid employment. The agencies trying to support them have limited funds, so when you go to these meetings - like yesterday - you're trying to find who can pay for what part of the support that is required; who has got some money that can do this; who are the experts to assist. That becomes quite difficult.

MRS OWENS: Say you're talking about a very violent kid this 15-year-old - sounded like he had some real problems - can you deal with that by just having more support people to be with that kid in the classroom, or in the school, or is it more than human resources?

MS McMULLAN: No, it's not always human resources. Sometimes you can buy personnel and - you can't actually buy the trained personnel you want, but you can buy personnel to do the support with the classroom teacher, but you need very skilled professional support and training for those people to do it well. What we find in our endeavours is the difficulty of getting that. Yesterday we had five experts in autism at this meeting and two of them were his main carers.

MRS OWENS: So even with the two main carers and perhaps some additional resources, it was not possible to put him back into a school. Say there had been the resources - in the ideal world where money was available - would there be a way of educating this kid? This kid is going to miss out.

MS LYNCH: A lot of it is that we don't have many alternative models of education. A lot of students, like Jeanette has spoken about, don't fit our standard class in a high school, or school model that we have. It's about - often at these meetings - trying to put together some package, an educational package for the student within the structures that we currently have.

MRS OWENS: And we need to think about different structures, is what you are saying.

MS LYNCH: Yes.

MS McMULLAN: And different agencies involved to support that structure, because it's not just about education. You need other agencies around there that can support as well, to do that. For some young people we put together some of these flexible packages. We have them going to or being enrolled in Open Access, which is our long-distance education mode, whereby they do a couple of subjects there through tutoring programs with Open Access and support from a school assistant or teacher's aide.

We have part-time attendance at school so we can maximise their attendance and regular attendance by saying, "They don't have to attend full-time every day but these are the components that work." We put in programs like - for some young people we know that rest in the middle of the day will work. If they come out of a (indistinct) environment, have some time in a very low-key environment and rest will work. So we build in sleep times and we can build in a whole range of different support structures, but it's not traditional, and you need a range of people to do that, plus you need flexibility and funding.

This year for the first time, for example, I've been able to access funds so that I can employ someone outside of education to do some jobs in education whereas previously I've not been able to do that. So that's a bonus. It's not always we have the expertise to manage some of the things we're asked to manage. That probably picks that up - in all of this you have teachers saying, "I'll put a default notice on the student" - which they can't do - but they'll say that. Their care is paramount in all of this.

MRS OWENS: Some of these costs will fall back on the school, too. You talk in your submission about reasonable adjustment, the cost of reasonable adjustment. Some of these costs will fall back on the school and we've been hearing from other organisations, like the Association of Independent Schools, that in the case of individual schools this can be quite a hardship to the school because of the lack of resources, or we're hearing that there are more resources going to the government schools than the independent schools. Even there we're talking about limited resources.

MS McMULLAN: Yes.

MRS OWENS: Regardless of how it's distributed.

MS McMULLAN: Schools do bear additional costs for these students, as do their staff and then you build in the notion that I've mentioned on the funding model about compensation. There is that feeling that is creeping into our schools now that if I have Johnny then I want - so you're always negotiating around what additionally you can find. "If you can't provide, we won't have." That is so much more common than it was five years ago. So the notion that by having a young person with disabilities in the school they have to not only just receive - they have to receive additional funding and then more.

MS McKENZIE: More than actually the child requires? So is it like a compensation - - -

MS McMULLAN: Sometimes I feel, as a negotiator in those circumstances, that I'm paying money to protect something that may in fact not in reality happen. In order to say, "You'll be fine" - okay, they are saying they are not - then perhaps we could do this at the beginning and then review it in a couple of weeks' time. Often they are quite satisfied with that, but it is like fear of the unknown. It is a funding factor there. Also recently I've had a school raise issues with me because there is one young person who actually exited the private school and came into the local school and was causing quite some degree of distress for the teacher. The teacher is now very stressed because she feels like her reputation is at stake because she is being questioned about how she's doing and what she's managing.

She has had a number of parents complain and saying, "If you don't get this child out of the classroom we'll be going to another school." You have a whole range of things happening and, even though we know we've put in a range of support structures - not just dollars and funding, but personnel, advice, time to plan and think and everything else that's going in to try and support that and maintain that - there is that and it's stronger. It's stronger for me than it was five years ago - these degrees of resistance that I am feeling through trying to support the young people.

MS McKENZIE: Do you think the situation is going backwards?

MS McMULLAN: I think with the occupational health and safety atmosphere - there is a big emphasis in our state on that and particularly in our schools - I really think that has made employees, and rightly so, aware of their rights and responsibilities about safety and duty of care. The other issue that has come into our schools, and possibly across Australia, is the notion of basic skills testing and achievements, and where is all the time and energy going. Where is a teacher's attention going?

MS LYNCH: I would just like to make the comment that a part of that - I could say "attitude" - is also reflected in society generally where there has tended to be a shift towards looking after yourself and less of that, I guess, village atmosphere of caring for people. I wonder if there is some reflection now that we're seeing in our schools because we say schools mirror society.

MS McKENZIE: That's a very interesting and worrying issue to raise.

MS LYNCH: Yes. On the other hand, I think also in terms of say the Disability Discrimination Act, it has had some positive outcomes in schools. It has certainly made people more aware of their practices and, whilst there probably still exists some subtle direct discrimination - for example, a parent with a child with a disability goes to a school and is not made to feel welcome - body language, et cetera, from senior staff - that's the discrimination. But, for example, we have what's called "special classes" within mainstream schools in our state and many years ago that special class was sometimes call "the opportunity class" and tended to be housed at the bottom of the oval in an old transportable and was never considered to be part of the school culture or whatever.

One of the schools I work in has one of these special classes and it is just included in the school; it's another class in the school. They access any of the whole school activities; they participate in new initiatives for the whole school, That has probably been a move perhaps the DDA has helped to progress.

MS McMULLAN: I would support Margaret on that. There are lots of very good practices and the DDA has moved a long way in our schools for at least making them think about many things like that - in relation to excursions or going-out activities.

MS LYNCH: That's right. Years ago, a child in a wheelchair or a child with really challenging behaviours - parents were just asked perhaps to keep them home that day, whereas now most people in schools know that if you're planning to take a class or a group somewhere and you have a child with a disability within that group, then your pre-planning must include how you are going to accommodate the needs of that child. Children with disabilities are accessing school camps now and things like that, whereas a few years ago we wouldn't have had that.

MS ALDERTON: Certainly the curriculum design now for students with learning disabilities has been significantly impacted by the DDA. Teachers are becoming much more aware that there need to be differentiation for those students and they do need to be included, so it's not just disability; it's learning disability, as well.

MRS OWENS: So there are positives and negatives - we're hearing - aren't there?

MS McMULLAN: Definitely positives. I wouldn't want not to have the DDA. It has made a tremendous difference for young people with disabilities.

MRS OWENS: We're looking at the DDA, as you know, but we're looking at ways that, if anything, it can be improved; if there are things that could be done better.

MS McKENZIE: If it's not effective in measuring up to its objectives, how can it be made more effective to do that?

MS McMULLAN: One of the things I'd say on that one is more staff with special education and expertise in disabilities, learning disabilities, and social and emotional behaviour disorders. The number of staff and personnel who are well trained in those areas is falling and you would know that from the numbers of universities that can offer those courses that are available.

MS LYNCH: Another point I would like to make there is there is certainly an easier means for collaboration between agencies working with these people. Not just - you know, for education to be working with what we call "human services help" or whatever. A lot of that time delay occurs because it can be difficult to get that collaborative approach to these students, as well.

MRS OWENS: You want the agencies in different areas - they're all silos, but even then - - -

MS LYNCH: That's right, yes.

MRS OWENS: - - - within areas like education, you have got another set of silos, haven't you?

MS LYNCH: That's right.

MRS OWENS: They've all got different programs; there are Commonwealth programs and state programs.

MS LYNCH: Different criteria for this and that.

MRS OWENS: Different criteria and it all gets very complicated.

MS LYNCH: Yes.

MRS OWENS: The previous participant said there's always a chance that things fall through the cracks.

MS LYNCH: Yes.

MS ALDERTON: If we're talking about cracks, I think one of the significant issues often overlooked is the capacity of families to cope for extended periods of time, and siblings of students with disabilities and learning difficulties in particular. That's frequently overlooked by agencies and schools.

MRS OWENS: That's what I was saying before when you gave the example of the young boy - the 15-year-old. I do worry about the family because really what that is doing is pushing the responsibility for that kid 24 hours a day back on that child's parents - - -

MS McKENZIE: And siblings.

MRS OWENS: And siblings. That's a very, very difficult thing for that family to have to cope with, and it's a question of what responsibility society needs to accept, vis-à-vis the family.

MS ALDERTON: Certainly in terms of siblings there's the whole issue of their performance at school, their social, emotional, and health and wellbeing, as well. That's often overlooked because it is actually about survival and quality for another member of the family. I'm not saying that's wrong, but it is very difficult.

MRS OWENS: That's the reality, yes.

MS ALDERTON: That's right.

MS McMULLAN: The fourth one was inconsistent funding and support arrangements. It probably speaks for itself. Within our education sectors which we are representing here - which is both government and non-government - it's poles apart, miles apart. For us, for government schools, it means that there are more students with disabilities there. Our student population across the state is roughly between 6 and 7 per cent of students with disabilities in government schools, and that is reasonably high, so the numbers are significant there.

MRS OWENS: Is this because of the incentives to go into the government schools because - - -

MS McMULLAN: Or lack of incentives in private schools because of a lack of options available, less funding, less assuredness about what support will be available for them.

MS ALDERTON: I frequently, in my role, receive phone calls from parents and families talking about what can the government sector offer and, although it may be limited at times, it's often perceived to be better than the current situation the child is in in a private setting.

MRS OWENS: But then that raises another important issue for parents and that is one of choice.

MS ALDERTON: Yes.

MRS OWENS: And potentially limited choice whereas other parents do have greater choice. It's always limited because it is going to depend on the resources in the family - whether they send children to a private school or a government school - but if you have a child who doesn't have a disability your choices are greater than if you have a child with a disability.

MS ALDERTON: That's correct.

MS McKENZIE: And here, the funding makes the choice limited irrespective of your family income. It doesn't matter whether you have lots or little, if you have a child with a disability your choices are limited because of the funding issue.

MS McMULLAN: Yes. I also get concerned about the almost ghetto effect of some of the public schools in that case. Again, I can only talk about my experience where I work, which is in the north. The average student with a disability of the population in the north - the state average is six - it's 15 per cent, so it's high. We have schools that are higher than that again. I get concerned about that and therefore - I suppose it speaks for itself in terms of what I am trying to say.

Agencies are also different. It's not support arrangements. It's also about the agencies. What are the agencies that are available to support even within our country districts? Limited support to our country centres from agencies that are Commonwealth funded, such as the Autism Association, or some of those agencies because of the funds that are available. All schools can't receive the same kinds of support either. That would be different - as Margaret said in her first example to you - of the young family coming from Queensland. All the agencies have different criteria for how they support families. We have different criteria in how they support schools.

MS LYNCH: The criteria even differs around definition of a student with a disability between states, as well, and that's a classic one.

MS McMULLAN: And between government and non-government schools. I don't know if we need to say much more on that. The last thing on the summary points I would like to say is about - though I strongly support any notion of documentation in individual education planning or NEP planning - negotiated education planning, as we call it in this state - - -

MRS OWENS: What does NEP stand for?

MS McMULLAN: Negotiated education planning. Though I fully support that I know in terms of time and productivity it's a big task - it's a big ask. If you have lots of students in a school who have disabilities then you're doing that many, many times over for students. We would have some high schools with 90 students with disabilities.

MS McKENZIE: Do you need an individual plan for each? Is that how it works?

MS McMULLAN: Yes, that's right.

MS LYNCH: If it is going to be used as a working document it needs to be reviewed regularly. At high school that can be quite a difficult thing to do in terms of - if a student is coming into contact with four, five, six subject area teachers, and all staff working with the student knowing what we're saying their goals are, what strategies we should be using, et cetera. That comes back to the point Jeanette made about the time constraints placed on best meeting the educational needs of these students.

MS McMULLAN: Those times are not paid times in terms of any funding arrangements that I can see. Schools don't get funded to plan with agencies and services that are there to support them. That comes out of the costs of their own school budgets to do that.

MRS OWENS: So you are really concerned there about the paperwork, but are you saying that there shouldn't be such planning or are you just saying that - - -

MS McMULLAN: I'm saying there should be such planning because it is vital for the young person and it is vital for their teachers. It assists the teachers with compliance with the DDA. There should be such planning. My concern is that how, in the busy life of a school day, unless you have ways in which you can release people to do that - and funds therefore to release people to do that - how is it managed? What we're finding is that some of the inconsistencies and grievances parents raise with us, through parent advocacy groups, is about schools not following through with the plans, and it's just about time really.

MRS OWENS: It's a resource issue once again.

MS McMULLAN: Yes, it is.

MS LYNCH: I think that's probably a summary of the issues that we wanted to raise. We are quite happy to answer any questions.

MRS OWENS: I thought that was a very useful guide to your submission and I would actually like to - if you don't mind - have it as a supplementary submission.

MS LYNCH: Yes.

MRS OWENS: Having gone through those points, because you've raised some points in a different way to the original submission and there is a lot more material in here, if you wouldn't mind it being tabled as a supplementary submission.

MS LYNCH: No, that's fine.

MRS OWENS: We will put it into the system.

MS LYNCH: We are just checking our paperwork - - -

MS McKENZIE: Yes. You've said how valuable the DDA is. Have any of you had experience with the complaints mechanism?

MS McMULLAN: I have.

MS LYNCH: Yes.

MS McKENZIE: Okay. Here comes a whole new set of - do you want to tell us a bit - without particularly identifying people - about your experience?

MS ALDERTON: We've had a number of instances within the role that I have, where we have had complaints from parents and they have gone through HREOC. In our particular directorate we have a very well-established process for handling that, and really it comes back to gathering people together from the schools, the centres and any other service providers, and working through a mediation process so it doesn't go further than that. I'm not sure if that's what you want to hear.

MRS OWENS: So not go beyond but try and sort it out - - -

MS ALDERTON: Not go beyond into civil action.

MRS OWENS: Before it goes to HREOC.

MS ALDERTON: Sometimes we have complaints that we can negotiate and discuss so that it doesn't get to HREOC; other times we get a formal complaint.

MS McKENZIE: And then it goes to conciliation.

MS ALDERTON: Then it goes to conciliation and our assistant director usually identifies a particular group of people within our directorate to work through that process.

MRS OWENS: So in terms of some that have gone to HREOC, can you just comment on the HREOC processes? Was it at the perceptions of those people that went through HREOC? We are interested in how that process is working and we're also interested in the barriers that people face in going to HREOC to put in a complaint in the first place.

MS ALDERTON: Generally speaking, and this is very limited experience, I would say that probably the cases that I know have often been cases where parents and families have been concerned for a number of years until finally it gets to the stage where it can't be tolerated any longer before a complaint is made. That is generally the case in my experience, but that's not necessarily for everything. What I have seen and heard is a great deal of stress and anxiety on the part of everybody involved in the process, and there seems to be, in the initial stages, some significant anxiety about who is involved and what happens, because people don't have a very clear understanding of the process itself. Once people have that process explained to them it's about, "Let's go with the stories first," and then have some discussion around that, there seems to be some lessening of anxiety although it is still a very stressful situation.

MS LYNCH: It reminds me of a situation one of my work colleagues is dealing with at the moment where there is a complaint made to HREOC. In this information-gathering, getting-together sort of thing, again it's that time - it's a very complicated thing to be doing when you're trying to mediate. My also limited experience is that people have become quite polarised in their views of what should be happening for a student, and that's when the HREOC complaint is made. So you've got people a long way apart and you're actually trying to bring them back together. There are stresses involved just in that process, let alone perhaps, for a lot of people, being part of the HREOC process and being unsure of it. There's all those kinds of stresses and the impact that it has on everyone, including the family. It's not just the education people involved.

MS McKENZIE: Is there any way to lessen the stress involved in that process?

MS LYNCH: Also, by the time people go to a HREOC complaint, their emotions are generally running fairly high anyway and I would suggest that adds to the stress levels.

MS McMULLAN: My experience, and I've had a couple - I've lost my train of thought, sorry.

MS LYNCH: Stress in the conciliation process or stress as a whole?

MS McMULLAN: Yes, we are polarised by that time, because I'm representing my organisation and I'm trying to support the school and the issues, so that we've done all our things properly, we've got all our procedural bits ticked and we've done everything right that we need to have done. By that time we are polarised, because we're into defending our positions by then. I find that really difficult. There are lots of times when all of us would say, "I wish the parents would go to HREOC," because we find some issues and we try to move around those. It's very tense, and I think you are polarised by that point of view, because you're wearing your agency hat by that time, your employer's hat and there are concerns.

Sometimes, with the ones that I've been involved with, it is how the parents have formalised their complaint so what is being investigated is really not the underlying issue, and what doesn't come out sometimes is that issue. We had a situation where the parent went - in relation to suspension of a student who had autism. What he was really challenging was our department's suspension exclusion policy, but what in fact was looked at and examined, and what the outcome was, was really about the processes that were used. So it's how he worded his original complaint I expect and the issue - rather than that he in a way accepted what we were doing as being what we had to do - because that was the procedure set by our department, but not about the policy. So it comes back to, sometimes, the wording or trying to find out more deeply what is the issue that is concerning the parents putting in the complaint, so that can then be examined, rather than what seems to be the purpose.

MRS OWENS: But that's where the parent probably needs really good advice.

MS McMULLAN: That's right.

MS McKENZIE: Also you would hope that if there is conciliation the conciliator might be able to go - that's their training - to the heart of the matter rather than look just at the almost artificial legal framework of the complaint, which is really just the top layer. What about the question of disability standards, in particular an education standard under the DDA? Have you got any - - -

MS McMULLAN: Our association has diverse opinions on that and I suppose those working in public education and private education have differing opinions on standards.

MS McKENZIE: And since your association represents both, does that make it rather difficult?

MS McMULLAN: We haven't, as an association, been consulted about the standards yet, so what we have been able to gather we have gathered from web sites. We haven't had an opportunity to discuss that as an association and have a view - - -

MS McKENZIE: So really you don't have a view?

MS McMULLAN: No - - -

MRS OWENS: Although you have a view in your original submission - you did mention something about it in your original submission - - -

MS LYNCH: Positively, but the downside is that if we have standards is it in fact not going to lead to best practice? People won't aspire to the best possible outcomes for the student. Will standards be just a minimum that people will reach?

MS McKENZIE: That's a point that has already been made quite strongly as well in some of this commission.

MRS OWENS: Another interesting point about the education standards is that if they are introduced that could actually raise the bar in terms of what skills are required to do, and that has additional resource implications.

MS LYNCH: Yes, that's right, definitely.

MRS OWENS: You did raise the issue about the piecemeal approach to developing standards so - - -

MS LYNCH: One has to be alert for opportunities to respond to inquiries or participate in those kinds of situations for our association to have some input into the developing of the standards.

MRS OWENS: Okay. Is there anything you wanted to raise with us Ingrid, Margaret or Jeanette?

MS LYNCH: No.

MS McMULLAN: No.

MS ALDERTON: No.

MRS OWENS: Thank you very much for coming.

MS McKENZIE: Very interesting submission.

MRS OWENS: Sorry for holding you up at the beginning.

MS LYNCH: Thank you for the opportunity to speak to you.

MRS OWENS: Thank you.

MS McKENZIE: Thank you.

MRS OWENS: The next participants this afternoon are Michael and Denice Bassanelli. Could you please give your names, repeat your names and the capacity in which you are here for the transcript.

MS BASSANELLI: I'm Denice Bassanelli and I'm just a private individual.

MR BASSANELLI: I'm Michael Bassanelli and I'm here as a private individual.

MRS OWENS: Presumably connected to each other.

MR BASSANELLI: Yes, Denice is my wife.

MS McKENZIE: By marriage.

MRS OWENS: Michael, or Denice, I understand you'd like to just summarise your submission or make a few key points from your submission for us.

MR BASSANELLI: Yes, sure.

MRS OWENS: Thank you.

MR BASSANELLI: Back in July 2002, Denice won a trip to Japan and we applied for travel insurance with a major Australian insurer and because she has metastatic cancer we assumed, as had happened in previous applications for travel insurance, that they would just exclude her pre-existing illness, the cancer.

MRS OWENS: You declared it when you made the application?

MR BASSANELLI: Yes.

MRS OWENS: It's on the form, isn't it?

MR BASSANELLI: Yes, it's on the application form. We filled out a preliminary medical appraisal report - I think is what it's called. Then, to our surprise and shock, it came back and they refused the policy in total.

MS McKENZIE: For any condition.

MR BASSANELLI: We were not allowed - they would not issue a policy full stop.

MS McKENZIE: Did you take the trip and then take the risk of - even that you might lose your luggage and not be insured, for example?

MR BASSANELLI: After that we went to an insurance broker and he was able to obtain a policy quite easily. It was - yes, so that was that.

MRS OWENS: So really your concern was just with this one particular insurer.

MR BASSANELLI: Yes, we only applied once and got knocked back once.

MRS OWENS: Then went to the broker, found another insurer and managed to get some coverage.

MR BASSANELLI: Yes, quite easy. Basically what we did after we came back from the holiday - we thought that - at the time it wasn't really fair, so we looked on the HREOC web site.

MRS OWENS: How did you know about HREOC?

MR BASSANELLI: I knew HREOC existed, but I didn't actually know much about - didn't know anything about the DDA, but I've learnt quite a lot since then. Basically we went through the web site and looked up disability discrimination and sought to see whether Denice would be qualified as being disabled with her cancer and we looked through and saw parts that we thought would make it justifiable to make a complaint, downloaded the complaint from the web site and sent it off to HREOC and then we basically went through an exchange of letters. We sent letters to HREOC and the insurers sent letters to HREOC and we ended up in conciliation in February this year.

MS McKENZIE: Without saying anything about what actually was said there, have you got any comments about the conciliation process; did any part of it worry you?

MR BASSANELLI: No, it wasn't that it wasn't what we were expecting. We were told that the insurer would say something and then we could say something. What we found, which we didn't know about at the time, was that we actually couldn't ask questions of the insurer. It was done by telephone with HREOC being in Sydney, the insurer was in another state and we were here in Adelaide. What happened was that the insurer would talk and then the conciliator would talk and then we would talk and sometimes the conciliator would disconnect us and talk privately with the insurer, and then they'd disconnect from them and the conciliator would talk privately with us.

MS McKENZIE: Would you have preferred to be face to face.

MS BASSANELLI: Yes.

MR BASSANELLI: We asked to be face to face.

MS McKENZIE: It wasn't possible, or - - -

MS BASSANELLI: I think it was just too hard because we were all in different states.

MR BASSANELLI: We basically wanted them to be face to face so that they could look at Denice and see that she wasn't dead yet - basically.

MRS OWENS: Can I ask, did the insurer have legal support there? Did they have a solicitor?

MR BASSANELLI: Yes, they had a solicitor from a very big legal firm.

MRS OWENS: What about you?

MS McKENZIE: Did you have one?

MR BASSANELLI: Yes, we went to the community legal service and we had two solicitors that helped us leading up to the conciliation. They had nothing to do with the preparation of the complaint, but they did help us in the weeks leading up to the conciliation and they sat in with us at the conciliation, which was done at their office.

MS McKENZIE: So you were at their office and then everyone else was in a different state, the commission was in one state, the insurer was in another state.

MR BASSANELLI: Yes.

MS McKENZIE: So matters didn't work out at the conciliation, and what happened after that?

MR BASSANELLI: Basically there is only - yes, what happened was that the complaint was terminated and the HREOC found in favour of the insurer. Because we were looking at section 46 of the DDA, which deals with the goods and services and the insurer's argument was under that section

46, the second part, that - I'll just find the exact words - that the discrimination is reasonable, having regard to any other relevant factors.

MS McKENZIE: HREOC thought also, did it, that that section applied to - - -

MR BASSANELLI: Yes, HREOC - they basically agreed with the insurer that the medical evidence was grounds for denying all the insurance that was - - -

MS McKENZIE: And you've now appealed, I gather. Is that right?

MR BASSANELLI: Yes, we've found a solicitor who is interested in this issue and is going to the Federal Court later on this year.

MS McKENZIE: Moving away from the actual complaint for a minute, first, what changes do you think should be made, if any, to the DDA to - do you think that because of this some changes should be made to the DDA?

MR BASSANELLI: I suppose our problem was the words "reasonable" and "relevant". Obviously I'd term them as being "loose". My interpretation of the act was that I would have thought that, okay, they could discriminate you on the grounds of your disability if it was reasonable, but to discriminate against you on things that had nothing to do with your disability I thought was obvious in the way the act was written, but maybe it's not.

MS McKENZIE: So you think it should be made clearer.

MR BASSANELLI: It should be made clearer. It would be nice to have a bit of guidance as to what is reasonable and what is relevant. There's only been one case testing this section 46 of the DDA, and that was here in Adelaide a couple of years ago.

MS McKENZIE: And it wasn't quite on that part of that section, was it, from what your submission says.

MR BASSANELLI: That part of the DDA there are two sections - you can discriminate, if you have statistical or actuarial data which is the part 1, and then part 2 is if you don't have statistical and actuarial data. That case was with the data and our case is without, so to my knowledge this part of the act has never been tested in court.

MRS OWENS: I suppose there are two ways that we could go in terms of our recommendations: one is to say those terms "reasonable" and "relevant" and so on, need to have some clearer definition in the act or interpretation; the other is to say that there should not be a part 2; that they can only discriminate on the basis of proper actuarial data - whatever that is. There are issues about what actuarial data the insurers use as well. But the other part of that clause really could be seen as just a let-out clause, that virtually allows them to do anything really. I don't know whether you've got a view on whether that part of section 46 should be there at all.

MR BASSANELLI: There are some things, I suppose, that they haven't got hard and fast actuarial data on, but they could have medical - I suppose medical experience would be - they can use. But, yes, it is a bit of a cop-out. In that part of the act that gives them an out, certainly, which is probably what has happened to us.

MRS OWENS: There could be some sort of new disease where there is not the data available yet, because not enough research has been done, but the research indicates although there's not exact data, that there are some very serious risks associated with it - it might be then reasonable perhaps, I don't know, for any insurer to take that into account. But what I'm now saying is that is much narrower than the way the section is at the moment.

MR BASSANELLI: I don't know if that's what the parliament intended it to be. When you write these things you might have an intention and it doesn't actually turn out that way, so this is - this review, from us, is a really good idea. You can see how it has worked and then maybe tighten it up around the edges a little bit and just see what happens. That's one of the main reasons why we came along, because unless we came along you wouldn't have been aware that this court case is coming up, or you probably would have found out - I don't know whether it goes on the HREOC web site if there is a determination, if it's still pending for court. I don't know whether it ends up on the web site, but you wouldn't have probably been aware of what's going to happen and it seemed like it was probably very important to the success of the outcome of this inquiry.

MRS OWENS: Yes. The other thing is we have talked about the conciliation and you said you would have preferred it face to face. Is there any other thing in the process, not what the complaint is about, but just in the process that you thought might perhaps be improved in any way?

MR BASSANELLI: It took about seven months, which I don't think was a really long time, but for someone in Denice's situation, you don't really want to have this going on and on. Unfortunately it's going to go on - we've been at this for nearly a year now and stress is not good for Denice, because of her illness and it causes stress amongst the whole family as well, every time you have to write a letter or do another document. So it hasn't been good from that point of view.

MRS OWENS: It would be good if it could have been made faster.

MR BASSANELLI: Yes, but seven months, like I say, is probably not that slow. It's just for us it would have been nice to have had this wrapped up and neatly packaged away and we could have got on with our life, but it hasn't turned out that way.

MRS OWENS: In some of the other states, in Victoria for example, there is a mechanism under the equal opportunity legislation where you can ask for your complaint to be expedited - that is, fast-tracked - and for fast-track complaints there is a very short timetable that has to be followed for conciliation and everything. There are circumstances in which you can ask for fast-tracking and they are set out, and basically if there - there's got to be some reasonable chance of being able to conciliate the matter and there's got to be some special circumstances or sexual harassment - that's not relevant in the Commonwealth case, but would you think that might be one way of - - -

MR BASSANELLI: We didn't know that was available.

MRS OWENS: No, it's not available in the Commonwealth, to my knowledge.

MR BASSANELLI: Yes, that would be good. I imagine there is a fairly high workload and a lot of competing interests, so someone would have to actually sit down and make that decision, but I don't suppose - yes, it was all right, but I suppose one other thing I was thinking about, back on the conciliation, is that we sort of wondered why we bothered, because it was really just an exchange of letters and when we got to the conciliation, they talked, we talked but you know, there - I don't know. We don't know what the conciliator said to them or - we know what they said to us, but there was no - to me conciliation is sort of like a negotiation, and you try and work towards a solution to the problem. But basically they weren't willing to negotiate full stop and I suppose that's the reason why nothing actually happened. To me conciliation - I wouldn't have called it conciliation, it was like an exchange of letters and an exchange of statements but there wasn't actually any conciliation.

MS BASSANELLI: I think they kept stressing that they don't want any surprises on the day and they didn't want to build up unexpected expectations and things, but I felt that we were flexible and I don't feel the conciliator - I don't know, was - - -

MS McKENZIE: It wasn't a completely satisfactory process.

MS BASSANELLI: No, it wasn't. It was just more stressful, like I guess emotions were running high, like the previous people said, and maybe we did have unexpected expectations because we thought it would have all been dealt with, but then we found it was just a waste of time.

MRS OWENS: Can I ask you, Denice, about the stress. Would it have helped you - instead of putting yourself through this - or you and Michael through this process - would you have found it more useful if you could have gone to another organisation and said, "This is the problem I've had with this insurer. I've got this problem," and possibly other people out there in your situation with other diseases may have similar problems and that other organisation - say it was the Breast Cancer Network - could have taken that complaint on your behalf and on behalf of others and taken it through the system instead. So you were one or two steps removed, so that other organisation, the Breast Cancer Network or whoever, could have initiated the complaint.

MS BASSANELLI: Yes, I think that would have been good, because then you wouldn't have had to be having so much stress writing letters and all the unexpected stuff, I suppose. If they did that, they would know what to expect and be able to inform you better as well.

MRS OWENS: You see, yours is just one voice in the wilderness, if you like.

MS BASSANELLI: It is, that's right; whereas if a group did it, it would be many voices.

MRS OWENS: And the outcome can be confidential so that the next person who comes along with the same problem may not have ever known that that had happened and might confront the same problem, whereas if it's a broader group bringing it, it's more likely that the industry will change its behaviour more generally. It might have been just the one insurer where the problem lay, it may not. I don't know.

MR BASSANELLI: In our research recently - this problem isn't just related to Denice. We've seen on the Internet that people with mental health problems have trouble getting travel insurance, insulin-dependent diabetics have trouble and so do people with cancer. We have found our insurance industry here, they don't have a code of practice, whereas in England they do. It's called the Association of British Insurers. They actually have a document telling insurers how to treat people with disabilities. It was written in conjunction with the DDA of England, which was 1995 or something, so the insurers and the disability people all got together and made a document on guidelines for insurance, how to write insurance for people with disabilities and medical problems. That would be a nice outcome in Australia, if the Australian insurance industry followed that. That's leading to exactly what you were talking about: having some kind of organisational guidelines for the insurers to do that sort of thing.

MS McKENZIE: Did anyone ever mention - the insurer, for example, when they knocked back the application originally - that there might be some insurance complaints body you could go to?

MR BASSANELLI: They have their own internal complaints things, which we could have gone to, but because a lot of people that we know - you tend to gravitate towards people with cancer. That's where your friend network actually ends up at this stage, so we knew a lot of people who have breast cancer and have been knocked back at insurance, so we knew it wasn't an isolated incident. I suppose taking it to HREOC actually opened the issue up to the wider community - well, not yet. It's still buried, I suppose.

MRS OWENS: You have, just by being here today.

MR BASSANELLI: Yes. But ultimately, yes, it's now maybe brought it up as an issue and there's a lot of people out there that have been refused insurance and therefore, yes, hopefully we're doing it now - originally it was, as I say, a bit of a thing, it was a bit personal because they really hurt Denice. Now it's a matter of principle that, you know, the community out there is being, we think, unfairly treated on this aspect.

MS BASSANELLI: And just the way that I've been treated, I don't want others to have to go through what I've gone through. At least by bringing it to the fore, people will become more informed and know that there is a problem.

MRS OWENS: There is another approach. You just mentioned the UK guidelines, which we'll go and have a look at - sounds like a very good model. But there is another approach that's been adopted. The Mental Health Council of Australia has got a memorandum of understanding with the Investment and Financial Services Association. I don't know if you've heard about that memorandum of understanding.

MR BASSANELLI: No.

MRS OWENS: We've got a few details about that and we'll be following up how that's going. They've just reached an agreement about procedures and the approach the insurance industry should be adopting toward people with mental health conditions, so that's another approach. It needs to be evaluated to see how well it's working. The other point I'd make to you is that we will be talking to the Insurance and Financial Services Association when we do our Sydney hearings, so we'll raise your submission with them and ask them if they would provide us with some feedback on your submission. I think they may take an interest and hopefully we will make sure that these sorts of examples don't occur in the future.

MS McKENZIE: One of the things we're looking at is whether that can be improved, to make it operate more effectively. That's one of the many things that we can consider as far as that is concerned.

MRS OWENS: Another issue - you did mention that you received funding for the case because of the public interest aspects of the case and we're just interested to know where you got the funding from and how you knew about the financial support.

MR BASSANELLI: We don't actually know how much it is. We haven't asked the solicitor. We sort of left it with him; but we actually went through our local member of parliament and he got in touch with the federal Attorney-General's Department and he also wrote a letter. He thought it was in the public interest. When you look at the other case, the Fortis case, the federal magistrate talks about this same issue, that section 46 - it was in the public interest. So that's I suppose where we got some of the idea from but we basically got it through our local member. I don't know if you want me to name him.

MRS OWENS: Just we're interested in the process more than the names, but it sounds like your local member did a very constructive - - -

MS McKENZIE: A very good thing to have done.

MRS OWENS: Thank you for bringing your particular situation to our attention. I'm afraid it's just more stress for you to go through but I hope we haven't made it too stressful for you.

MS BASSANELLI: No.

MS McKENZIE: It's really helpful to come and talk to us about it as well because it's really adding to your submission, so it's really helpful to us.

MR BASSANELLI: The whole idea was to make the issue - the issue needs to be brought out in amongst the wider community and sort of higher authorities than us that can actually probably get something done and make everyone in the general community aware that this problem is there and maybe there are people out there who would like to help and get it resolved. As I say, reviewing this, the DDA, is one way of doing it or making these insurance-type documents, get a code of practice like that. That would probably knock 99 per cent of these things on the head straightaway. So we're very pleased to have the opportunity to come along.

MRS OWENS: Thank you both very much.

MS BASSANELLI: Thank you very much.

MRS OWENS: We'll break just for a minute.

MRS OWENS: The last participant this afternoon is Mr Christopher Dugdale. Could you please repeat your name for the transcript and tell us the capacity in which you're appearing?

MR DUGDALE: I'm Christopher Dugdale. I'm here in an independent capacity. Basically, I've come to just share my experience. I don't know how relevant it is to your inquiry. I did read the background information that Patrick sent me. First-up, I heard about this more than a month ago. I was hoping to make a written submission, but actually my health was terrible and I was in a bed a lot. A week or so ago when I made contact - I have been having acupuncture and, fortunately, I've sort of stabilised enough although I won't be able to write anything - I thought I could at least come and say my experience.

MRS OWENS: It does get written, because it goes onto the transcript.

MR DUGDALE: That's right.

MRS OWENS: So we do have something in writing. That's beaut!

MR DUGDALE: I thought I would like to structure what I say in three steps: first, paint a little picture of what life was like before I had a disability and then a short picture of what it's been like since and then some of the issues that it has raised. First-up, I guess my first experience with a little disability was I had about 18 months on walking sticks and stuff in my late teens due to a rock climbing accident. At the time I went to Flinders University and I would have to go up 13 flights of stairs to get to my first lecture, which was a very long, slow process. To catch a bus there, I had to catch the first and only bus, which was often full and didn't stop. In other words, I had huge problems accessing my education at that time. In fact, I think it slowed things down a bit.

My experience recently has been quite different to that. I would like to say I've worked as a volunteer in New Guinea. I was also in a seminary for three years. I've done very extensive volunteer work for about a decade with the Scout Association. I've been very lucky and been exposed to many many opportunities that aren't normally available to people. Therefore, I speak three or four languages, none from my ethnic background. I'm an Italian-Lebanese-English-Australian. My father sort of says, "Well, you should say English first," and I say, "Well, you weren't actually around when I was a kid." In fact, all my relatives here are Italian and Lebanese.

MS McKENZIE: What languages do you speak?

MR DUGDALE: I speak sort of a Creole which is used on the Eyre Peninsula up through to the West Australian border and - I don't know that I remember any of it, but I used to be very fluent in Papua New Guinea talk - pidgin - and Japanese. I spent about seven years in Japan. In my young life, I did a lot of study - about eight or nine years at university - and mostly working half-time and studying full-time or the other way around.

I had many nice opportunities. I was able in the seminary to be exposed to many things that were kind of unusual and have many interesting experiences. I became a teacher and fairly quickly wanted to go overseas; worked in Japan; was the fastest ever promoted person in my company and was in charge of head office four years after I arrived, with the largest teacher of English and foreign languages services in Japan, which is owned by NEC and is, in fact, the largest company of its kind in the world and is now a bit of multinational, because they're doing things in China and elsewhere.

In Japan I was exposed, of course, to a lot of opportunities and met the heads of many large corporations. I was most particularly impressed by the fact that I didn't get a job definition, particularly when I went up to Tokyo and accepted full responsibilities for my role. My boss said, "Look, you've got a whole lot of skills. Your boss can't even describe them to me. Everything you've worked on has been just going magically. We want you in our head office. Bring what skills you've got to the head office and create your job and you'll be supported in it."

That was literally the contract that I went up there. It was only a sentence or two long, like that. In fact, he always supported me in every decision I made at all times, basically because he'd made this initial agreement. This is very common in Japan. It is not a job-centric and role-defined sort of thing. It's saying to virtually anyone, "Look, we've got a job here and these are the basic things that have to happen within that job, but anyway you bring your knowledge and skills and if you do it the same way as the last person we know something is wrong. In fact, you will not get promoted ever again and things will be very hard on you, because you're expected to bring your own knowledge and skills." Of course, the roles of the job change a little; very different from here.

I came back to Australia. In fact, I resigned after seven years because our president made a number of statements in public that were racist. I was offered a very handsome amount of money to stay; resigned anyway and am very happy that, in fact, the company has changed its practices. I left there in 1995. I was speaking to the director just two or three days ago and we have a good relationship, partly because they made sure that they did understand the issues that I'd raised and they did address them. I'm very happy that the company is perhaps one of the very least racist in Japan now and has excellent policies.

I came back here and worked in a bank for a while, partly because I was interested in improving my database skills. The very last night of working in Japan was the first night that I collapsed. I've had this condition since 1986, but towards the end of 1995 - my last night working in Japan - I actually physically collapsed and couldn't walk. That was the first time I knew I was going to be in for a really hard run. About 1999, I think, I actually had to resign and I haven't been able to work since.

Working here was quite different. I found a very supportive employer, again, who basically said, "Well, we can't understand what you do, but that's okay because you solve a lot of problems for us." In other words, both in Japan and when I came back here I had the ideal employment situation, because I could dictate my terms of existence. One of them is I never work more than 40 hours a week, because I have had a thing that's been ongoing for a long time.

Even though I was working for a bank, which is normally restrictive, I had a 24-hour pass. I started when I liked, I finished when I liked and I took the most absurd lunch breaks when no manager would dare take an hour-long lunch break, you know. I had a very supportive situation and the bank was very keen, as I was starting having really serious problems, to say, "Look, you've got so many skills you can work anywhere in the bank." Of course, a bank covers almost every possible job you can imagine. You know, they've got posties and they have educators and they have everything else. They were very keen to help me stay within their organisation - worked very hard to do so - but it had turned out I'd had a step up in this physical problem and really I needed to stop working.

I have a fantastic medical team here. One of the reasons why I'm here is that we have the best craniofacial and maxillofacial surgeons in the country. They and my neurologist and GP form a fantastic support team. There are no drug and no surgical intervention options for me. We have a clear picture that only my face muscles are spasm-ing. It's just muscular, it's just the face and it's also the most extensive case ever recorded by Prof Goss at the Royal Adelaide.

It means now that, although I have many problems - I'd like to move onto describing some of the things that impacted me because of a disability. The first thing I noticed since 1995 - I've been attacked in the streets at least once a year every year since. That's never happened to me before. I'm a big fellow and I can generally walk as though I can carry myself in a fight, although I've never been into fighting. The attacks range from a group of 10 people trying to take my jacket through to someone attacking me with a knife and literally hold it four inches from my throat. I got out of it, basically, by bluff and, because I have been around, I know a few tricks, but I certainly didn't fight in those cases. I simply used my knowledge of the streets to sort of talk my way out of it.

MRS OWENS: These happened, both, in Adelaide?

MR DUGDALE: In Adelaide. Like I say, it's been basically at least an attack every year since I've been here and it never happened anywhere before in my life. I had a group of six youths come up and stand around me and say, "Give us your wallet, cunt." Excuse the language, but that's what they said. I had no intention of going anywhere without the wallet. I was smoking a cigarette. I've stopped, thank you everyone. I put the cigarette out on the back of my hand, staring at the guy who had just spoken to me and said, "I don't think I'll be giving you my wallet." He said, "By God, that's tough," or something like that and they all parted and let me through, so bluff again. There are a number of other instances.

MRS OWENS: Maybe you should take up smoking again so you can do it again next time.

MR DUGDALE: No, I only stopped six or seven weeks ago, and I'm very happy that I've stopped.

MRS OWENS: I've just found one positive reason why - - -

MR DUGDALE: I tell you what, it's not a bad reason to carry a packet of cigarettes. It works brilliantly, because if you put it out hard and fast - the tiny burn I generated had cleared up within two days and it didn't hurt. I was pumping so much adrenalin, nothing would have hurt. I take it that one of the reasons that I was attacked - and, by the way, on 27 December 2001 I was attacked in front of police officers by a couple of people that the officers had just thrown out of the pub. They walked across the street, saw me, hit me from behind up here and then started kicking me in the head. Kind of silly, since the police were watching from just across the road, but anyway - - -

MRS OWENS: Did they do anything to intervene?

MR DUGDALE: I can't remember actually getting attacked. I can remember struggling to my feet with a police officer in front of me saying, "Stand there. Right, don't move. Stay right there." At that time, the other four or five cops were fixing up these two guys, taking them away in a paddy wagon. Then the policeman who talked to me said, "Look, are you all right? You were just kicked in the head." I didn't say, "I don't believe it," but I did not believe it. My head did not hurt. I couldn't feel anything at all. I had clearly been hit in the head. I had a graze on my forehead and I had lumps up here and all around the back of my head, but anyway at the time I didn't know that. He said, "Do you want to go to hospital?" I said, "No, I just want to go to bed," and he left me to walk home. I have since discovered that every ambulance officer and every police officer has clear instructions that if someone is kicked in the head they must make sure they go to the hospital, by force if necessary.

Then were there another few incidents. That particular one - of course, I ended up doing a victims of crime thing and I'm told I might get 1 or perhaps 2 thousand dollars. If I hadn't have been disabled, the lawyers I spoke to said very clearly that this would be worth very large amounts of money, because it happened in front of police. There may well have been police liability, because the police had literally just thrown the people out of the pub. It was all on videotape, because it was in Hindley Street.

But anyway, both lawyers I spoke to advised me that in fact it would be a very, very minimal payout and I would be lucky to get anything more than the minimum, because I was disabled. I was shocked to hear that, and disgusted. I appreciate the victims of crime legislation does in fact largely just try and replace some lost salary or lost income. Since I hadn't had any to lose it didn't really apply to me, but I haven't actually formally heard the outcome of that. I am supposed to have heard weeks ago, but at some time in the next month or two I will hear what the result was from the Attorney-General's Department.

MRS OWENS: I presume it's more than loss of income. That's pain and suffering.

MR DUGDALE: I can't remember the first half of last year, and as far as I know I repeated the same day every day for six months. I spent three to five hours a day trying to read and not being able to understand a word, and at least had the wherewithal to keep doing that and now I can read and understand what I read. Because of the really weird problems I get when my face spasms, muscles anywhere in my body can tear themselves - largely by exercises, by keeping everything balanced, by doing stretching and things every day, which takes more than three or five hours a day - one of the reasons I had to resign, it had got to be all night after work every night and all weekend every weekend just to be able to go to work.

So I had to resign because I was just overloaded and basically I've got two full-time jobs just caring for myself now. Certainly at the moment I would
be looking for much more stability before I look for any kind of employment role. I want to be able to read and write and I want to be able to hike again. My doctor says if I go near a swimming pool he will sign a thing that says that I can have a little bit of - what do they call it? The water therapy stuff - - -

MRS OWENS: Hydrotherapy.

MR DUGDALE: He said he would sign the thing for that, but he doesn't think I should go near water, because I have a tendency to spasm in it and I might - look, I used to surf every day. If I could I always swam before work all my life, and before school. I just want to be able to swim again. If it's the start of a process that helps me do that, I think I should try it if I can get access to hydrotherapy. He's like, "Look, it's not going to happen, but anyway I will back you if you choose to do it." That's one reason - I've got a wonderful medical team. They are very understanding and they support me very strongly.

Sometimes I go in and I don't make any sense at all, because I'm in too much pain. Certainly Prof Goss, who is the surgeon, is very strongly of the opinion that although I'm much worse than anyone else in this state or this country the reason I'm looking after myself is because I don't take any drugs. There are many people in nursing homes with just minor parts of the problems I've got, and there are many people who need carers and things who have much simpler problems than I've got with my face.

MS McKENZIE: So tell me about the other issues that are associated with the disability. You've mentioned the one about being attacked numbers of times in the street.

MR DUGDALE: I think it's sort of partly because I can spend a bit of time - I used to spend a lot of time walking down the street like that. Notice I have a leer on my face. I don't know if I - I might have had a bit this morning. I can't shut the mouth always and that was a bit of a problem. So I think partly it's how I present walking down the street. I do literally collapse on the ground and can't get up. I carry a card to sort of show people and that. The other day I walked up to Bunnings. It's only a 10-minute walk. Took the dog up, fine. I tied him up near the entrance of Bunnings. Fine, no problem. I walked in and collapsed two metres inside; basically couldn't breathe, was seeing stars and stuff, worked through the exercises I know that I need to do at that sort of time. Half an hour later I went down the back of the store to check out the price of something that I went up there to find out. I had to head straight back to the seat near the front entrance, stayed there for another 45 minutes and then took over 45 minutes to do the 10-minute walk home.

That's the example I used with the doctor and he sort of - basically I didn't really realise that I could get some assistance with transport, so I very often - if I had to come into town - when you're disabled you also tend to be poor. In my case, quite often I have to come into town because I can't afford to make a phone call. If I collapse it's like - I can be in town for three hours or five hours. I can't get onto a bus. Certainly in the situation I was in the other morning I quite often will ring a friend and say, "Look, I'm really confused, I'm not breathing well, I don't know where I am, I don't know how to get home. Can you come and find me?" I can read off street signs. I grew up - I was born half a kilometre down the road there. Then I sort of just stay in the same place until - Robbie is the most likely to get called - comes and finds me and sort of gets me somewhere where I can be looked after a little.

MRS OWENS: Do you want to talk about your experiences with ambulances and going into the emergency departments of hospitals?

MR DUGDALE: Yes, I haven't actually ever called an ambulance, partly because I've been very scared to go to hospital. But one day I went to my GP and sort of said, "Look, I can barely walk, I can barely talk, I can barely breathe and this has been going on for more than a day." I tend to stay home in that situation, because it's so hard to get to the GP, and at the moment I'm applying for taxi tickets and stuff so that I do get to see them when I'm really bad. Anyway, he gave me a covering note, sent me to the emergency section at the Royal Adelaide. After a short time they took me out the back and the next thing there was some young doctor standing there about to inject me.

I knew I should have been asked whether or not I was going to allow an injection. I didn't know what the drug was. I said, "You have to ask me about injecting. What the hell is that?" I forget the name of it, but it's an anti-drug drug they use. Basically they use it for everyone who they suspect of having used drugs, and it neutralises virtually any drug very fast. He was about to inject me with it. A bit of a problem. First-up, I hadn't used any drugs and they hadn't asked me if I had. They hadn't talked to me at all in fact. They just came along and were about to shove this needle in my arm. Secondly, one of the reasons I take no drugs is that I react extremely badly to virtually every class of drug that I've tried and that can greatly impair my ability to talk, walk, breathe and take care of myself. So I refused this needle. He had it a millimetre from my arm. On another occasion my reaction would have been too slow to stop him injecting me.

MRS OWENS: If you had been in the middle of a spasm you might not have been in a position to tell him - - -

MR DUGDALE: In fact if he had been half an hour earlier, when I was more locked up, I couldn't have done a thing, because I still couldn't talk.

MS McKENZIE: Yes, that's right.

MR DUGDALE: In fact I've just been liaising with Prof Goss and the administrators at the hospital to reconcile my records and get my Royal Adelaide Hospital records up to date, because I need to get a MedicAlert bracelet and it needs to refer to those records and make sure that I don't get any drug treatment at least until my records have been sighted, so that it's quite clear that by and large they shouldn't inject me with anything and that the spasming and what is apparently severe addictive - I don't know, when people can barely walk and talk because they have overdone drugs - it might look like that, but it's not related, we do have a known cause and it's just part of my regular part of life.

I just want to very quickly run through a number of problems I have. First-up, because I bought a house and, for various other reasons, I had about eight contacts with my local council staff in the space of one year last year, more than half of those contacts were extremely negative for me. I had council staff laughing in my face, because I wasn't speaking very clearly. You know, sometimes I get to speak like this and appear a bit intense.

MRS OWENS: That doesn't come over very well on the transcript unfortunately.

MR DUGDALE: No, but talking very, very slowly and very perhaps slurred. Not necessarily clearly.

MRS OWENS: Yes.

MR DUGDALE: At the same time as probably having weird expressions on my face, poor tone control, poor volume control and sudden variations in tone and volume that don't match meaning. I actually followed that up with the council and I believe they have taken reasonable efforts to solve the problem, but I was shocked that of eight or so contacts with council half of them could have been negative. I was absolutely appalled that any public servants could treat me like I was treated by a number of people. In fact, I had one come to the door and said to me very politely, "Look, excuse me, you've got the dog lying out the front. Technically that is common land, because you live in flats. I just want to let you know that on another occasion I might have to fine you or something for that."

MRS OWENS: What were you doing?

MR DUGDALE: My dog was lying out the front of the house and I'm in a block of flats, so technically it's common land. She was just driving past and noticed, and kindly dropped in to tell me. What she didn't need to do was repeat it another four times, because I said, "Okay, thanks." Then I didn't reply when she said the same sentence the second time, the third time or the fourth time. After the fourth time I said, "You've just said the same thing four times. I'm not an idiot. Why are you doing this?" She said, "To make sure you understand." I was furious. By this time her assistant had turned up in his car and he just sort of said one sentence, which was effectively, "Look, we're just here to do our job," or something. He was trying not to get involved. I could see by the look on his face he was shocked when she repeated herself the third time. He knew it wasn't appropriate.

Anyway, having said that, walking back to the car she started off again and I ended up making a written complaint and it was solved reasonably, I think. There were also quite a number of other things like that. When I was settling on my unit, on the afternoon I made the appointment with the solicitor I was really having a lot of problems breathing. I lost the note. I didn't know what time settlement was. The following week I called the office of the solicitor three times simply to ask, "What time am I settling on my house? What time do I have to turn up at the office to pay the money?" On each of those three phone calls - I can't remember them well, but I do know that I was unable to find out and even two hours before settlement on the day I still didn't know what time my settlement appointment was, because they had refused to tell me.

I dashed off a short letter - I suppose it would have been HREOC - and no doubt it didn't make much sense, because it only took about 10 minutes and I wasn't probably in a very good state to be doing anything at the time. Anyway, I got back a generic letter that effectively said, you know, "You go and see a lawyer, otherwise forget about it, because you haven't put this clearly enough." I thought a five or six-line letter that says, "Look, I went to this mob, made an appointment and then I rang them three times the following week and they refused to tell me when the appointment was," I thought that was kind of weird and it would have got a response. Anyway, I let that slide.

My local fish and chip shop was real nice when I moved in. I used to go down there once or twice a week. In fact, I make it a bit of a habit of making sure I use local shops when I move into an area, having travelled a lot and moved to a lot of different cities, getting to know them. I'd sort of make sure I went twice in one week and then, if I'm not going to go the next week, so they'd remember me and that. I got very good service for about three months and then the proprietor sort of brought up, "Oh, you seem to have a lot of free time. Are you on a pension or something?" I said, "Yes." He said, "Are you disabled?" I said, "Yes." The next time I went there he refused to serve me.

MRS OWENS: Why?

MR DUGDALE: I don't know. He said it was because I only wanted one dim sim and I was like, "Well, all I've ever come in here and done is buy one dim sim or one piece of fish, because that's about all I ever do." So in fact over months my order hadn't changed, even though it is a small order. He just decided to refuse after he clarified that I was disabled, and he did use the word "Are you on a pension?" and the next sentence was, "Are you on a disability pension?" And then I couldn't get service. I didn't follow it through or anything. I wrote him a one-line note saying, "Can you please explain your behaviour yesterday?" but then I didn't follow it through more and, of course, I don't go there any more. Not that he'd serve me if I did. I went to the deli - - -

MRS OWENS: We are going to have to finish in a minute because we have to be out of this room and go to the airport.

MR DUGDALE: Just the very - - -

MRS OWENS: I would like to hear your other issues.

MS McKENZIE: Can you summarise them?

MR DUGDALE: Actually they're the main sorts of issues and I just wanted to sort of mention a few and then the thing that raises for me is I've had so many incidents, each one of which could be a full-on complaint; each one of which would have taken my efforts to organise it, to be involved in it, to do something about it. I'm battling to live day to day and that is the key problem. Everyone, I'm sure, who has a disability gets to be in this sort of position, where you need an advocate. You need an advocate for something that happens every single week. You know, you can have a complaint literally nearly every week, that would be valid to follow through, and yet it's not possible.

What I want to say really strongly is that I don't think that necessarily the sort of legislation that has been introduced helps people as much as is thought, just as moving people from Glenside to community facilities, tends to mean there is one manager for 36 people instead of people getting reasonable attention. If you've ever visited guest homes it's like - it's just appalling. For people in my position at least I can't necessarily defend my rights to access anything because I don't have the time to initiate action on my own behalf or to follow through the legal processes and anyway, where is the money going to come from?

If I wanted to make a complaint against the fish and chip shop guy, maybe I'd have won, but if I didn't, I might have had court costs. I don't have money for that sort of thing. I was very sort of a little bit ashamed listening to the guy in the wheelchair here earlier, because there's a lot more - he took action and on each thing I'm just like - I couldn't possibly risk losing, it'd be too expensive, and I don't have the wherewithal to actually act on my behalf. I'm trying to work out shopping and cooking and I'm trying to be able to wash up every day.

MRS OWENS: Mr Corcoran is still in the workforce.

MS McKENZIE: Yes, that's a big difference.

MRS OWENS: That probably makes a big difference.

MR DUGDALE: Yes, I'm sure.

MRS OWENS: I think he has a very significant disability but I think his doesn't - yours is a much more unpredictable disability.

MR DUGDALE: And, as I discovered, extremely rare in that I don't have a prognosis-diagnosis or anything.

MS McKENZIE: They just know that there is some problem but they can't - - -

MR DUGDALE: They know that my muscle spasms and the extent of it is massive and that it's very unusual but they don't know the cause. They don't know how to stop it or to limit it.

MRS OWENS: I'm really pleased you gave us that.

MS McKENZIE: Yes, thank you very much.

MRS OWENS: You've given us some really useful insight into how you live and I'm very pleased you've got it on the transcript. I'm sorry we have to stop you now.

MR DUGDALE: No, I was aware I was only up for 10 or 15 and I think I've taken somewhat more than that.

MRS OWENS: You've done very well.

MS McKENZIE: And thank you very much for attending. I think you've stayed from the very beginning to the very end, so that's - - -

MR DUGDALE: That was my personal challenge, you see, because I've been in bed for the last three months and it was like, well, if I can just sit there - I should be lying down for half an hour every hour, so - because my neck keeps going into spasms. I have achieved something that I feel good about.

MRS OWENS: Thank you.

MR DUGDALE: And also I've heard a number of things that have encouraged me and inspired me and thank you both for the way you've handled this inquiry.

MRS OWENS: Thank you.

MS McKENZIE: Thank you very much.

MRS OWENS: I'll now adjourn the proceedings and we'll be resuming in Sydney on 14 July at 9.30 am. Thanks for that.

AT 3.58 PM THE INQUIRY WAS ADJOURNED UNTIL
MONDAY, 14 JULY 2003

INDEX