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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO THE DISABILITY DISCRIMINATION ACT

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

TRANSCRIPT OF PROCEEDINGS

AT MELBOURNE ON TUESDAY, 22 JULY 2003, AT 9.30 AM

Continued from 18/7/03 in Sydney

MRS OWENS: Good morning, and welcome to the public hearing for the Productivity Commission inquiry into the Disability Discrimination Act 1992, which we refer to as the DDA. My name is Helen Owens and I'm the presiding commissioner on this inquiry. My associate commissioner is Cate McKenzie. The hearing will have breaks for morning tea, lunch and afternoon tea. We will need to stick fairly closely to the timetable. You are welcome to take a break and enter at any time if you need to. Our commission staff will assist you with anything you might need during the course of the day.

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 disability 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've already talked informally to a range of organisations and individuals with an interest in these issues and submissions have been coming in to the inquiry following the release of the issues paper in March.

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've held hearings to date in all capital cities and we're holding hearings in Melbourne this week, as our final week. 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 the hearings in a reasonably informal manner, but I 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 wants to speak I'll be allowing time at the end of the 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 in Melbourne to appear - Wendy Kiefel. Could you just repeat your name and the capacity in which you're appearing for the transcript.

MS KIEFEL: I'm Wendy Kiefel and I am here today as the parent of a young child with autism.

MRS OWENS: Thank you.

MS McKENZIE: Wendy, we're happy if you call us Cate and Helen, if you're happy that we call you Wendy.

MS KIEFEL: Certainly.

MRS OWENS: Thank you for your submission and for coming today at this early hour. We really do appreciate it. Do you want to make any points about your submission?

MS KIEFEL: Yes, I do, Helen. I've just got a brief presentation that I'd like to make. Before I begin, I just wanted to make a minor correction to one aspect of my submission. I've mentioned, I think, in paragraph 6 that families attending the early intervention centre, Irabina, are required to make a co-payment of $1300 per annum for their child's treatment. This is the fee that our family pays and we're in the charity funded program. I know that the government funded program also requires a co-payment, but I don't know what the annual fee is.

MRS OWENS: Thank you for that. You wanted to make some other comments.

MS KIEFEL: I do, yes. I make my submission to this inquiry not as an expert in the law, but as a parent of a child with autism, so my submission does not contain bulletproof legal argument backed up with evidence and precedent. I'm here to tell a story about what I think is entrenched discrimination and the way that it affects my son.

The terms of reference for this inquiry state that the commission is interested in cases where failure to provide a service to a disabled person leads to discrimination. I think that this is an important issues, particularly relevant to children with autism. The lack of adequate early intervention for children with autism causes more profound disability than would otherwise be the case.

I'd just like to spend a minute talking about autism and what it is. It's a disorder where the parts of the brain governing sensory perception, emotion, social interaction and communication, have not developed normally. People with autism find it difficult to interact successfully with other people. They may also find it difficult to tolerate sensory stimulation that is present in a normal environment. This leads to dysfunctional behaviour and that is the disability - the behaviour.

In the same way that typically developing young children can adapt to their environment and learn to communicate, control their emotion and socially interact, so too can a young child with autism. The brain is a remarkable organ and, at a young age, there are remarkable powers of recuperation. The difference is that whereas a typical child will learn incidentally from normal day-to-day experience, the child with autism requires more structured and supported learning opportunity. If these opportunities are made available at a young age - and I believe that experts would say that window of opportunity is between the ages of two and five - then a child with autism can be rehabilitated to the point where they have many functional skills and many - not all, but many are able to lead independent and fulfilled lives.

It’s common that children with autism learn from visual cues, rather than language - that’s the key difference. Just as a brief example I’ve brought along with me a little book that we used to teach my son how to behave himself when he goes shopping; not to run away. It’s full of pictures, very simple language. A speech pathologist put it together for me after talking to me about his behaviour and what our needs are. You can see it’s very visual, very clear what he needs to do.

MRS OWENS: It’s little photos, Cate, and under each photograph they have just a few words describing what needs to happen. There is one here of a little boy and he’s about to do - - -

MS KIEFEL: He’s holding the car and waiting.

MRS OWENS: And he’s waiting, and there’s a little sign saying "Wait".

MS KIEFEL: Yes.

MRS OWENS: It’s a nice little book - but she put it together for you?

MS KIEFEL: Yes. So parents need to learn how to relate differently to their child with autism. This can involve a dramatic change of approach - certainly it did for me and my husband. Consistency is important, so every member of the family - brothers, sisters, grandparents - need to change the way they relate to this child. Making the change requires significant professional support. Just because you’ve had a child doesn’t mean you’re an expert in raising that child, and that’s especially true when you have a child with autism.

When parents of a young child with autism turn to the state for help they often find that government has opted out of providing this help. This has very serious repercussions for the child. If a child presents to the doctor with a serious condition that requires urgent treatment in the health system, the community considers the system negligent if that child is allowed to develop a serious and lifelong disability because of the lack of adequate treatment. Fortunately for most of us this is really just a hypothetical concept. Our kids do tend to get the treatment they need in a timely fashion but the lack of treatment is a reality for kids with autism.

I've mentioned in my submission that services have been dramatically reduced at the early intervention centre our son attends. 10 years ago Irabina - that's the name of the centre - offered five full days of service per week. This has been progressively reduced to the point where our son can only access three hours of service per week. This reduction in service has occurred because of government decisions to underfund the centre. It has not occurred because the needs of children with autism have diminished.

So what impact does the limited service have on my son's disability? I think one of the most important, in my mind, is his lack of opportunity to make friends. It's very hard for my son to make friends. In fact, he has no friends. His behaviour is incomprehensible to typically developing kids and their parents. He needs time, understanding and a lot of encouragement and support to make friends. He just doesn't get enough time at Irabina to make friends. Imagine what life must be like for a person who doesn't know how to make a friend, or how to be a friend.

Another way that the lack of service affects my son is that he has to spend too many sessions adjusting to the breaks and the changes in routine at the centre. Because we only go once a week, he has - kids with autism do tend to rely on routine and when the routine is broken they have to adjust, and when the routine re-establishes itself, they have to adjust again. That takes time - and our kids are working against the clock. So the time he spends at Irabina that he can work on his other important learning goals is restricted.

One of his most important learning goals relates to his preparation to attend school and kindergarten. It is the expectation of the education system that my son will be prepared for school when he attends. He has a lot of unacceptable behaviour and I know by talking to other parents that some of his unacceptable behaviours will be used as a reason for suspending him from school, so we have some very serious issues to work on quite urgently. I'd just like to finish this point I've made about Irabina by emphasising that I'm not criticising the centre, the wonderful staff or our generous benefactor there - Ron Clarke. All of these people are simply doing the most they can with the resources that are available.

How does government respond to our situation? We're certainly not the first family to complain. My husband has held discussions with our local MP, Tony Robinson, the member for Mitcham in the state government. Mr Robinson tells us that any increase in spending in disability services, no matter how big, is "scratching the surface". Basically he's telling us it's too hard. The government has discretionary power to provide the services we need, yet the government chooses to put the money elsewhere. Since I'm cynical, I'll say that it is often spent for maximum political benefit. In the political arena disability just doesn't have the numbers.

Children with autism need the protection of the law. Adequate provision of treatment for these children should not be left to the discretion of government. When government is allowed to exercise its discretion it has shown a clear preference for opting out. I firmly believe that the Disability Discrimination Act needs to be a mechanism for government accountability. Better outcomes for children with autism are possible in countries where the law specifies their right to effective treatment. In a recent Canadian case a Court of Appeal ordered the province to allocate sufficient funds for the earlier treatment of autism because failure to do so has unacceptably grave consequences. I included in my submission an article which I found from the Canadian Globe and Mail. I included it because it showed that when an independent body, namely the court, has the opportunity to objectively weigh up the arguments for and against, it finds that the government arguments of "not enough money" is less compelling than the arguments in favour of the child.

I'd like to close now by saying that our family has a huge task ahead of us, to guide and develop our son as best we can. Dealing with the lack of service from government, fighting bureaucracy and coping with the associated stress is an unwelcome and unhelpful burden which distracts us from the important task of rehabilitating our son. Thank you.

MRS OWENS: Thank you, Wendy, very much for that. I don't quite know where to start with this one. We're looking at the Disability Discrimination Act so maybe we'll try and bring the discussion to that. I think you've explained extremely well the difficulties you face and the issues relating to government service provision. I don't know if it's any comfort to you but I think that Mitcham is a fairly marginal electorate - - -

MS KIEFEL: Yes, I'm well aware of that.

MRS OWENS: - - - which may help, but obviously hasn't helped too much to date. Maybe that could work in your favour, but what we struggle with in this inquiry is that we have been asked to look at this particular act and what it can and can't do, and there's been a whole range of issues relating to government service provision that has been raised with us, and the question is how do we deal with those in the context of the review of the act and making a link between the lack of adequate service provision and discrimination, and I think as we've been going along - and Cate can say something, too - is that I think we're starting to see that there is a link. If children like your son don't get adequate services at this stage, it could lead to real problems for the rest of their lives, including discrimination both in the school context and possibly much later when they try and get into higher education or the workforce. Do you want to add anything, Cate?

MS McKENZIE: Yes, there are a couple of things that occur to me. One is that you might be asking for the amendment to the Disability Discrimination Act to make it clear that it will cover where differential services are provided or inadequate services are provided for, among other things, children with disabilities. That seems to be part of what you're saying in your submission, and that's one of the matters that is clearly within the scope of our inquiry, because submissions are going to suggest amendments that might be made to the DDA to make its coverage better or to make it work better. Am I right, that that would be one of the things - - -

MS KIEFEL: Yes, that is the point I wished to make.

MRS OWENS: Some people have argued that the definition of disability doesn't go far enough and that there needs to be account taken of behaviours resulting from disabilities, and I suppose you'd probably fall into that. There is actually a court case on right now looking at this issue, which you may be aware of.

MS KIEFEL: Yes, I am aware of that case, and I think that's a very relevant point. I believe that the Human Rights and Equal Opportunity Commission has a view that the behaviour should not be allowed to be separated from the disability, that that's a contentious matter.

MRS OWENS: I don't know that their view is that it shouldn't be allowed to. I think they're just saying if you interpret the law as it's written, they've got one particular interpretation of the law.

MS KIEFEL: Yes.

MS McKENZIE: The appeal shows quite clearly that I would have thought that the law is ambiguous, and certainly, one way or another, whether it comes through the decision or it comes through an amendment, I would have thought something needs to be done to make it clearer.

MS KIEFEL: Certainly, and I'd like to also make the point that in the education system kids tend to be considered okay if they're not misbehaving. Their learning is not really the issue. The behaviour is the issue. We're looking at a situation where we could apply for aid to help our son go to kinder next year, and I've been told that the criteria that will be assessed is whether our son is a physical danger to himself or a physical danger to the other children, and whether or not he learns anything at four-year-old kinder is not relevant to our application.

MRS OWENS: So the aid is there really to protect other children from him and protect himself from himself - - -

MS KIEFEL: Yes.

MRS OWENS: - - - rather than being there to help him with the education aspect of going to kindergarten.

MS KIEFEL: Correct. I'm sure that a competent aide will be addressing his learning needs but the criteria for giving him that aid - - -

MS McKENZIE: Is the safety.

MS KIEFEL: - - - is the safety.

MS McKENZIE: There are a couple of other things that occur to me. One is that if his behaviours aren't managed by early intervention then you've made the point that by the time he gets to enrol at school he may not be enrolable because the school will say those behaviours are too much of a safety risk, and claim that it would be an unjustifiable hardship for the school to enrol him.

MS KIEFEL: Yes.

MS McKENZIE: That certainly has a relation with the DDA because that's a defence.

MS KIEFEL: Yes. I'd also like to make the point here that there is the opportunity for a child with autism to attend a special school, but the child had to do an IQ test and will only be permitted to attend a special school if their IQ is found to be below a certain standard, so it doesn't look at behavioural needs, it looks at IQ.

MS McKENZIE: So you can fall within the cracks. Your IQ might be too high to go to a special school but the behaviour might be too concerning to go to a mainstream school, and you finish up with nothing.

MS KIEFEL: Yes.

MRS OWENS: So the special schools are there really for the kids with autism who have behavioural problems and A low IQ.

MS KIEFEL: Yes.

MRS OWENS: That's the criteria, rather than saying, "Let's look at this child's needs overall."

MS KIEFEL: Yes.

MRS OWENS: But would you want your child to go to a special school or would you prefer him to go into the mainstream?

MS KIEFEL: That's an issue that I lie awake about at night quite often. He has another nearly 18 months to go before he starts school. He's learning rapidly at the moment. His progress has been quite remarkable, and he may well reach a point where we feel quite happy to put him into a mainstream school. One of the dilemmas we face is that our family is privately funding an early intervention program for him, to cover the shortfall of government service, so he's learning his numbers, his letters, his colours, the names of body parts, et cetera, all the things that you'd expect a four-year-old child to know. We are lifting his IQ by giving him this therapy. Whether or not we'll lift it to a point where he wouldn't qualify for special school although he might need it is a real dilemma for us.

MRS OWENS: You don't want to hold him back just on the off-chance you might want to send him to the special school - - -

MS KIEFEL: No, exactly.

MRS OWENS: - - - because that's really not fair on him. You want him to develop to his full potential, and he might be a really bright kid.

MS KIEFEL: Precisely. In fact, many kids with autism are very bright. It's not necessarily an intellectual disability.

MS McKENZIE: It's a communication one.

MS KIEFEL: Yes, that's right. In fact some kids with autism that I've met - I look at them, I watch them, and I think, "I don't understand what's wrong with this child," and then I see something happen and then I understand. Something has gone off the routine and the child goes off the rails.

MS McKENZIE: So routine is very important?

MS KIEFEL: Yes.

MS McKENZIE: If you sent him to a mainstream school - because we've had a number of submissions about the differential funding of non-government and government schools - there have been all sorts of submissions that have said that - there have been some arguments about this, but is it your understanding that if you sent him to a government school there would be more funding to help him?

MS KIEFEL: Yes. In fact I received a letter from the Department of Education recently, telling me that we could have funding for an aide should we choose to send our son to a state school.

MRS OWENS: So that would become a factor in your - there's another decision. You've got two decisions: one between a special school and mainstream, and then the other is what sort of mainstream.

MS KIEFEL: Correct.

MRS OWENS: So would that tip the balance for you?

MS KIEFEL: No. The balance has already been tipped for us by the fact that we have to fund his early intervention, so we simply don't have the resources to choose an independent school for our son.

MS McKENZIE: Irrespective of what you might want, you just have no choice?

MS KIEFEL: Yes.

MS McKENZIE: If I'm right in understanding your submission, you talk about the lack of funding for early intervention treatment, and are you comparing that with other disabilities or conditions which are better funded?

MS KIEFEL: I don't know enough about other disabilities to make that comparison.

MS McKENZIE: I'm not asking you to if you can't do it.

MS KIEFEL: No. My answer is, I don't know.

MRS OWENS: You said in your submission that you thought that it was unjust that the DDA offers protection to the government or more protection than it does to young children with autism, and I was just wondering what you were inferring by that.

MS KIEFEL: Okay. I'm a member of a group called PEOAK, which is Parents for Educational Opportunities for Autistic Kids, and we decided as a group that we would like to speak to a lawyer to find out what we could do to help our kids in the education system, and I've had a couple of discussions with a lawyer from Public Interest Legal Clearing House, and she's told me that although our situation seems very unfair, there are probably very few avenues that we could pursue in the law. Unless we could find government policies that weren't being correctly applied or were being applied for one child and not another, then our avenue for legal action was very limited.

MRS OWENS: Because the laws covering the administration of government programs rather than the laws underpinning those programs - was that what the argument was?

MS KIEFEL: Yes. I have to stress I'm not an expert in the law, but my understanding is that because the government is a service provider, it would be difficult for us to take action against them. I don't know if that's correct or not.

MRS OWENS: Well, the issue of interpretation of the law is one issue which we'll be looking at, and the other issue is just that if you were say to put in a complaint, there's the imbalance between maybe the legal and other resources that you can bring to bear in a complaint vis-a-vis taking on a government department - - -

MS KIEFEL: Certainly that's an obstacle too. In fact, when we were talking about this, there were some families that had some pretty awful stories to tell, and we decided as a group that it's just too much of a burden on one family to pursue this, so we would prefer to pursue it as a group, and certainly we're batting way above our weight, if we were to take on the government in a legal sense.

MRS OWENS: Even as a group?

MS KIEFEL: As a group. The lawyer that I spoke to has foreshadowed the difficulty that we would find gaining representation, since many of the members of PILCH also act for the Victorian government. She didn't say there's no way, but she just foreshadowed that as an obstacle.

MS McKENZIE: If I understand your submission correctly, I'm right in saying that you would probably say that the Disability Discrimination Act hasn't been of any substantial help in your son's case.

MS KIEFEL: Yes.

MS McKENZIE: Has there been any change, do you think, you know, over the last number of years in community attitudes to people with autism?

MS KIEFEL: Well, to answer that question, I'll talk about a woman that I met last week, Junee Waites. You might have heard of her. She has a son, Dane, who is nearly 30 years old. She wrote a book, Smiling at Shadows, and I met her last week. She spoke to the parents at Irabina. She was a very inspiring speaker. The issues that she faced with her son are similar to the issues that we're looking at now. In fact, her son was able to get a lot more support than our son can get. He was able to attend Irabina until he was 10 years old, and then he was allowed to attend an autistic school.

MS McKENZIE: That school wasn't confined to those with a particular IQ.

MS KIEFEL: That's my understanding, yes. Our situation is that we can get three hours of support per week from a charity program. So have things changed? I think that might indicate that things have changed for the worst. I should maybe also mention at this point, when my son was diagnosed, the paediatrician who saw him held some very low expectations for him and in my shock and grief I asked this doctor, did he think that my son would ever talk. He told me that he thought I should accept the possibility that my son might never talk. He was only two. Now, to tell me that my son would never talk at such a young age - that could have had a real impact on my motivation to get him to talk. This doctor told us that the therapy that we wanted to pursue was a waste of money. He told me there was not a shred of evidence that that was an effective therapy.

We went and did our own research. We found that the Murdoch University in Western Australia had examined the therapy and agreed that it was an effective therapy to use. It really shocked and frightened me that an expert in the year 2001 would tell you that there is no hope for a child with autism.

MRS OWENS: Did you go and get other legal opinion?

MS KIEFEL: Absolutely, we did. We just couldn't believe that we should be abandoning hope for our son when he's only two. In fact, I'm delighted to say that our faith in him has certainly been borne out.

MS McKENZIE: And the therapy did work.

MS KIEFEL: The therapy works, yes. The next doctor that we spoke with, we asked her about the therapy and she told us she considered it to be an excellent therapy, but her only hesitation in recommending it to us was the expense. She said that she sees families taking out second mortgages, she sees families trying to do it all themselves and becoming burnt out and no help to their child.

MRS OWENS: But I think that's useful advice, because only you, the family, can balance that, but at least she was warning you.

MS KIEFEL: That's right. We deserve to know the facts and we'll decide what we can and can't afford.

MS McKENZIE: That's a great recommendation, I would have thought, for extra medical education, because if that's the advice - - -

MS KIEFEL: Most certainly.

MS McKENZIE: Presumably this is not the only doctor who might be giving such advice to parents.

MS KIEFEL: No, it isn't. We also saw a speech pathologist, who we no longer see, and she told me that she didn't think my son would suffer because - I think what she was inferring was that she thought he was too stupid to suffer. But suffer he does. He doesn't behave badly because he's a happy child; he is expressing his anger and frustration.

MRS OWENS: I think he's very fortunate to have you and you are obviously very understanding of his situation and I presume you must talk to other parents who have children like your son and share stories and so on.

MS KIEFEL: Yes.

MS McKENZIE: That's how PEOAK presumably must help.

MS KIEFEL: Yes, it does.

MRS OWENS: I think I've covered my questions as well. Is there anything else that you would like to add to your submission?

MS KIEFEL: No. Thank you for the opportunity.

MS McKENZIE: It's been a really helpful submission for us.

MRS OWENS: Thank you for giving us the Canadian case and the Supreme Court decision. Thank you for that. We'll just break for a minute.

MRS OWENS: We'll now resume. The next participant this morning is Associate Professor Frank Fisher. Would you please repeat your name and the capacity in which you're appearing today for the transcript.

PROF FISHER: Frank Fisher is my name and I'm not quite sure what you want of "capacity".

MRS OWENS: Are you appearing as an individual or as a staff member of Monash?

PROF FISHER: No, definitely not as a staff member of Monash but as a representative of very many groups, and I would like to table a list of those groups that I am involved in; in fact while I am in the business of tabling, I've got two copies of various bits and pieces.

MRS OWENS: Okay.

PROF FISHER: Do you want me to name them?

MS McKENZIE: You might want to tell me what the bits and pieces are. It would be helpful to me.

MRS OWENS: If there is a short, brief title, that would be good.

MS McKENZIE: Just a summary of it.

PROF FISHER: Yes. Firstly, there is that list of external committees I am involved in. There are about 20 of them. Most of them are related to disability, chronic disease and so on, like Consumers Health Forum, Health Issue Centre, Continence Foundation of Australia, on whose boards I have either been or am now. The next one is a whole series of newspaper articles I've had written over the years on chronic disease and the implications of it. Then of course there is the one I submitted to you - my article from the Consumers Associations Journal on the discriminating act. Then there are a couple of internal memos from Monash University about my situation, which I will mention briefly in a moment; a few papers on self-management in chronic disease that I have written over the years and, finally, one called From Being Precious to Precious Being, which more or less puts where I'm coming from

MRS OWENS: Okay. Thank you for that and we'll process those.

PROF FISHER: Thanks.

MRS OWENS: Would you like to introduce your submission? We have read it and have I think a pretty good understanding of the issues you want to raise, but if you want to bring out some of the key points.

PROF FISHER: Yes, and to make a few more if I might, please.

MRS OWENS: Yes.

PROF FISHER: First of all, just for the sake of the record, I have had Crohn's disease, which is a chronic auto-immune disease - at least it is in my case - for the past 40 years, so that is all my adult life. It has meant that I now have 85 per cent of my small intestine gone, so I live with chronic malnutrition and dehydration. I manage by dint of a lot of insight and assistance from the medical profession, the whole health industry, to live without an intravenous drip. Most people - in fact everybody - with as little gut as I have would have a backpack on and would be fed intravenously.

The point I want to make is that currently the act discriminates against the chronically ill; in fact it makes a second-class life out of it by excluding us from - excluding the insurance industry from the act. The insurance industry does not have to consider the likes of me at all, so it's not a matter of competition. There is no need to compete for the services - or at least the custom - of the chronically ill, the disabled, under the act. The insurance industry is, as far as I know, the only exclusion from the act and that makes second-class lives out of us and makes us - or at least the capacity to compete - the chronically ill, a good deal harder than it needs to be. That's the aim of my submission - to get people to think about that particular exclusion and, if possible, at least, to just exclude it - just to drop it. If not, of course, to turn it around altogether and make it positive rather than negative.

I would like to make just a few points about the implications of that situation before I allow you to question me, if you don't mind. One is I would like to thank whoever raised the act for consideration by the Productivity Commission. I know these things come via complex routes, but I would like to put that on the record: that I am very grateful that the act is actually being considered. That's terrific. I would like to also ask the commission to consider defining what it means by "competition" and what it means by "efficiency".

If you look under clause 3 of the terms of reference, 3(c), it asks there to look at the competition restrictive implications of the legislation, so I would like some discussion of the nature of competition there, which would then of course throw light on the interesting areas in which competition actually proceeds when you are disabled and the area which was brought to light in the Australian newspaper a few days ago - in the article which is part of my submission - a very interesting consequence of chronic disability is that one tends to overwork and so on and so on - and that reminds me. I apologise. I failed to mention a very early paper of mine written over 20 years ago, which makes that sort of point.

In my own case I have had to forfeit 300 days of holiday that has been removed from me by the university because I tried to stack it up to take in the event that I became sick and needed all of it in hospital and all the other places I've been in my life. Eventually the university had the option just to remove it, which they did. I have never had study leave in effect in 25 years at Monash and all of that sort of thing comes as a consequence of my own response to my disease and, of course, there are different responses. On the one hand, malingering; on the other hand, overwork, and I happen to fall into that latter group.

The other thing is to consider efficiency; what is meant by "the efficiency of the legislation". Okay. This business of second-class life needs to be considered; just what is the implication of classing people like us - like me - into that category of being, second-class life. We also need to isolate the implications of exclusion from insurance and I have done that in my paper. There are various implications of that - exclusion from life insurance; formerly exclusion from superannuation because we couldn't get the insurance component of superannuation, so we were excluded all together, which meant a decline in income, because of course the employer did not have to pay its component of the superannuation.

It of course means that we are discriminated against at work because we're always there. We can always fill in for others who can - in my case, let's say - take study leave, and there are various other insurances, as well; obviously travel insurance, the insurance that you get to pay you when you're not able to work - I forget the name of that one - and so on and so on. So any insurance where a medical certification is required - that's essentially the insurances we are excluded from.

Finally I would like just to make two points. One is that this internal requirement of the act to exclude insurance from the dictates of the act actually put that section, it seems to me, in contradiction to the rest of the act, which is an interesting little twist. How that could have come about under the act - well, of course, it wasn't under the act, was it, when it was written? Anyway, that's an interesting contradiction. Also I would like to point out the perverse incentive that it creates - actually creating a class of invalidity. I am invalid expressly under this act, and I resent that of course.

Finally, just the flip side of all of this - and of course I make this point also in my paper - I do concede that in fighting all of this stuff I have gained an awful lot. I've gained a lot of insight. Many of the committees I'm on are because of all of my struggles with my disease; one of the main ones being incontinence, and hence my involvement in the Continence Foundation. That has led to a lot of insight and a lot of strength in myself and of course has had a lot to do with the way I teach at the university in my environmental science work. This of course is all a bit of a joke because it's a case of loving your torturer, so I'm not advocating that, but nevertheless it has been the case. Thanks.

MRS OWENS: Thank you. With the section 46 in the act that you are referring to, you have recommended that it should be abolished. Another potential approach would be to change the wording of it in some way. The insurance industry - we spoke to one group last week in Sydney - say that you need some sort of exemption because the insurers should have the capacity to be able to risk-rate; that's what insurance is based on - this rating.

PROF FISHER: Absolutely, yes.

MRS OWENS: So the wording as it is at the moment refers to actuarial and statistical evidence and then other relevant factors. There's like a let-out clause there.

PROF FISHER: Yes.

MRS OWENS: One possibility is to let them continue to be able to make decisions so that they can risk-rate based on actuarial and statistical information, objective information, that look at this other clause that's tacked on their other relevant factors - whatever the wording is. Would you be happy with that approach or do you want to see the whole thing removed?

PROF FISHER: You would have to explain it a bit further, please. I can't understand why just deleting it wouldn't still allow them to do that.

MRS OWENS: It may.

PROF FISHER: Right.

MRS OWENS: I think we'd have to look at the wording of the rest of the act to see whether they would still be able to perform their duties as insurers because, as insurers - I mean, inherent in the insurance market is discrimination, where you determine different premiums for different people, depending on their conditions, and you in some cases exclude people from the market.

PROF FISHER: Yes, absolutely.

MRS OWENS: That's what risk-rating is all about, as distinct from say private health insurance, where we've got community rating and now lifetime community rating, where everybody gets rated the same, but the insurers will make the case that they need to be able to undertake a risk-rating approach and be able to use underwriters, otherwise they don't have a viable insurance market.

PROF FISHER: Okay, but there are all sorts of other ways of helping to support a very high premium. Actually I do have a life insurance because, even 30 years ago, I understood something of what I was getting into.

MRS OWENS: I was going to ask you that next.

PROF FISHER: It's a loaded one.

MS McKENZIE: So you pay a higher premium?

PROF FISHER: That's right, yes, but that loading could be provided by, for instance, an employer, and if you have read that exchange of memos between the vice-chancellor and me about natural justice in my case - having been there 25 years and never having study leave or travel, et cetera, et cetera - the university under certain conditions - I get from their memo - would be prepared to help fund a case like me, but the completely open funding - in other words, them taking over the entire responsibility for my insurance when I leave Australia - that they're unwilling to do.

MS McKENZIE: Yes.

PROF FISHER: The current situation - and I will go to my retirement this way - has been one of just total exclusion. That needn't be the case if insurance companies were willing to come to the party in some way or, conversely, employers willing to assist with the premiums.

MS McKENZIE: Perhaps what a halfway house, if you like, might be that insurers in those circumstances might be allowed to load - load the premium - but not to refuse to insure.

PROF FISHER: Yes.

MS McKENZIE: And certainly in your case - take travel insurance, for example - I assume you're refused all travel insurance?

PROF FISHER: Of course, yes.

MS McKENZIE: Rather than being given travel insurance but with perhaps an exclusion that relates to whatever might happen to you because of your chronic illness.

PROF FISHER: Yes.

MRS OWENS: Can I ask you: do Monash use a broker when they take out travel insurance?

PROF FISHER: Sorry, I don't know that because I have never come close to it. I don't know, sorry.

MRS OWENS: I mean, there are usually insurance policies that you can get that will say, "This policy covers you for everything but your condition."

PROF FISHER: That's right.

MRS OWENS: We have had other examples of people being denied - totally being denied - their travel insurance, and we had a case of a woman in Adelaide with breast cancer, who hadn't been able to get travel insurance from one insure and has put in a complaint under HREOC, which is going to go to the Federal Court but in the meantime went to a broker and got insurance elsewhere. That's why I was asking about Monash.

PROF FISHER: Yes, I don't know the answer. But there would be another possibility and that is that - the positive one in this case - the government actually tries to take some responsibility in this game and that it assists insurance companies or just assists the disabled under a whole lot of circumstances to gain the - not rights, of course - services that are currently excluded from us. Again, I'm just an amateur at this game and I haven't had the resources to - in fact the whole disability movement hasn't got the resources to study these issues. So I don't know what I'm talking about in this grey area.

MS McKENZIE: Have you ever considered it as a benefit of employment which the university gives to others, in effect, but denies to you? Have you ever looked at it as a discrimination case in that way?

PROF FISHER: No, good point. Thank you. That's a very good point.

MS McKENZIE: It seems to me that there may well be a possibility of discrimination actually by the employer.

PROF FISHER: That's interesting. It's taken me 15 years to get disability policy up at Monash for staff. We've had it for students, of course, for at least a decade, but we've now got it in front of the vice-chancellor finally for staff. I managed to get the disabled into the superannuation scheme when Monash joined the national scheme in the late 80s. I did that also, but other than - - -

MRS OWENS: Did you have to fight for that? I saw that in your submission.

PROF FISHER: Yes, very much so. The union assisted then, and since then the union has not assisted in any way and I've threatened to leave them and so last week, again after many years, I finally go to speak to the head of the union at Monash and she was appalled. She just hadn't understood - she probably hadn't read anything that I'd sent her - anything about this situation. She hadn't understood it and now she is taking it up thank goodness, but I had to threaten to leave for that to happen.

MRS OWENS: I think Cate's point about whether this is discrimination by an employer would be an interesting case.

PROF FISHER: Yes, it is interesting, certainly.

MRS OWENS: But I think it raises the issue of how the employer would respond to that case, which could be to say - Monash could put up an unjustifiable hardship defence and say, "For us to support Associate Professor Fisher and take his risk when he goes overseas, that's going to be too costly for us, if something goes wrong. We're not prepared to bear that risk." So they might try that one on. I don't know whether they'd win on that basis because it's a very large organisation.

MS McKENZIE: And also the consequences for Frank are very serious. There are a number of things to be taken into account.

MRS OWENS: Yes, so it would be a very interesting case. Would you be prepared to follow something like that through the system?

PROF FISHER: In terms of resources, no. My wind farm isn't paying that sort of money.

MS McKENZIE: But the other question relates to what you said earlier about your leave being taken away. A similar argument might apply, in the sense that with other people that leave can be used but for you, because of your disability, that leave not only can't be used but in many ways needs to be kept. It may be a question that the requirement which is made on everybody is one with which, because of your illness, you can't comply; in other words, it's an indirect discrimination.

PROF FISHER: Yes. I present the university or any potential employer with a whole lot of contradictions. How can you ride a bicycle if you're disabled? I'm non-visibly disabled. That's the point of that early paper that I wrote 25 years ago, and of course a lot of what I do I have to do to keep going under the conditions of my disease. I run up and down stairs to keep kidney stones moving, to reverse my osteoporosis, because I've been on steroids for 20 years, but I happen to have fit legs - that's about the only part of me that is fit. Anyway, all of these contradictions - yes.

MRS OWENS: I was going to say and a fit brain.

PROF FISHER: Thanks. But a lot of these contradictions make it very difficult for staff in high places to take seriously my application. They don't see what going to the toilet 20 times a day, they don't see that - digging holes in parks because the public toilets are closed out of hours and so on and so on. All of that's invisible - the 40 pills a day, the injections and on and on and on, the multiple hospitalisations every year and all of that is invisible. To make it credible takes a lot of time and effort.

MS McKENZIE: A number of the submissions that have been made to us do mention that, too. There are a number of visible disabilities, if you like - I mean, it's been mentioned on a number of occasions that people in wheelchairs - and I'm not in any way downgrading or detracting from the difficulties they experience - but the invisible disabilities, where they see you physically active, are in a way more difficult for people perhaps to understand.

PROF FISHER: Yes, and earlier on Joan Dwyer, who was the first head of the Equal Opportunity Commission here in Victoria, invited - I think it was Rhonda Galbally and me - to front on just that basis. She, to explain the difficulties of visible disability and me to explain those of non-visible disability. Interesting differences.

MS McKENZIE: Sorry, Frank, I'm just musing about whether there are other questions I should have asked you before.

MRS OWENS: Can I come back to Monash again. Is there a group of you at Monash who have all faced the same problem with travel insurance?

PROF FISHER: Thanks for raising that. When this superannuation - when I brought that on in the late 80s I did a survey with the union of at least all the staff in the union who were disabled. That was 70 per cent of staff in the university were unionised, or were then. Not a single person would admit to it. I was the only disabled person in the university. That is a very profound issue; that the chronically ill, especially the invisible, will not come out. That's a profound issue and it's one that occupies us a lot in the disability movement.

MRS OWENS: I was just wondering whether there were staff or others at Monash who are, say, in wheelchairs where their condition is more visible and where Monash takes a different approach - - -

PROF FISHER: I don't know.

MRS OWENS: To see whether there is a differential approach to the people at Monash, depending on their condition.

PROF FISHER: I don't know the answer to that and I've been on the disabled committee for the university for about 10 years now and I haven't noticed it. I think, in terms of how they deal with me within the normal day-to-day interactions of humans, it's fine. I don't have any problem with my employer in that sense, it's just here they can do what they're doing and they're doing it. The act condones it.

MRS OWENS: I'm just looking to see if there is anything else. One of the issues, as I said earlier, is that we'll be looking at this section 46 and we have got a number of other submissions relating to section 46 and the exclusion of insurance - most aspects of insurance anyway, and looking at whether you have an exemption or whether the wording needs to change. If you have any more ideas about that, it's just a matter of - as you rightly said, are there other aspects of the act that will pick it up without having to have it set out there in black and white, or does it help clarify the insurer's responsibility, because that is the nature of insurance.

PROF FISHER: Sure. The only thing I can do is refer you to an organisation if, in fact, they are not already presenting here and it is the Chronic Illness Alliance, who have had voluntary legal advice on the act. I know that's been going on now for about two years. How far they've got I don't know. It's not an organisation that I'm involved with in a day-to-day sense. The head of it is a woman called Dr Christine Walker and she is based at the Epilepsy Foundation, if I remember. But it is the Chronic Illness Alliance - it's a small national body.

MRS OWENS: I don't think they are appearing. I don't know whether they've put in a submission.

PROF FISHER: That's disappointing.

MRS OWENS: But we might chase them up and see if they're interested. They may not know that the inquiry is on, of course.

PROF FISHER: I'd find that hard to imagine. Okay, I'm sorry. It's not, as I said, one that I'm involved with a lot, but they have had legal advice, they have had a lawyer working in the background on some aspects of this issue for about two years now.

MS McKENZIE: The other thing to say, I suppose, is that one of the matters raised in our terms of reference is this question of self-regulation as an alternative to the provisions of - or at least to some of the provisions of the DDA. I suspect that you might say that really with this exemption, the insurance exemption, self-regulation applies. I think, if I'm right, you might say that it has not been very successful as far as your case is concerned.

PROF FISHER: Absolutely. Again, I don’t have any further comment to that.

MRS OWENS: What I'd say at this point is that we are interested in these particular parts of the act and what needs to be there and what doesn't need to be there, but you also made a really interesting point about what happens to people that do fall through the cracks, and I think you said that maybe the government needs to be thinking about doing something. What we are doing in our report is highlighting - we'll be addressing our terms of reference firstly and foremost, but there has been a whole range of other issues raised with us about service provision and adequacy of service provision for people with disabilities - a whole range of other things which don't technically fit within the confines of our terms of reference. This issue of what you do about people with disabilities if they can't get insurance, which means that then they cannot participate fully in life, in all life's experiences.

PROF FISHER: I'm not a competitor.

MRS OWENS: Yes.

PROF FISHER: I'm excluded from competition.

MRS OWENS: We will bring all these other issues to the government's attention. We'll have a part of the report which will say, "By the way, a range of other issues were raised and here they are." I'm just thinking aloud on that issue. At the moment there are provisions in insurance for reinsurance pools, for the elderly and so on. I'm just wondering whether there's something that could be done through the insurance system and if it can't be done through the insurance system then we do have other ways of pooling - like we do have the Medicare system, for example.

PROF FISHER: Yes.

MRS OWENS: As a public health insurance arrangement. I don't know what the answer to the problem is because I haven't thought about it, but there are I think opportunities for us to raise these sorts of issues and to say, "Well, there are these other important points that need to be considered."

MS McKENZIE: Perhaps even both ways - we'll still, of course, look at the insurance exemption, but this is an additional issue, if you like, that we might also look at. Helen is right, it's still a side of our inquiry, but the insurance exemption is not.

PROF FISHER: Thank you very much.

MRS OWENS: Thank you very much.

MS McKENZIE: It was a very helpful submission.

MRS OWENS: We'll now break and resume at 11 o'clock.

MRS OWENS: We'll now resume. The next participant this morning is Mr Tom Byrnes. Welcome. Would you like to repeat your name and - - -

MR BYRNES: My name is Tom Byrnes and I am a grandparent of a disabled little girl, who has cerebral palsy.

MRS OWENS: Thank you, and thank you for your submission.

MR BYRNES: It's my pleasure.

MRS OWENS: I'll hand over to you to just introduce it for us.

MR BYRNES: All right. Thanks very much. It probably rambles on a little bit, my submission. It takes a little bit of working out, but it's just my opinion that - well, the DDA does make it unlawful for schools to discriminate against students with disabilities. The legislation places the obligation on the schools to provide the appropriate facilities and programs for students with disabilities, but the Commonwealth and state governments fail to support the independent schools and the children with disabilities in their funding system, where they have no equality to go to a government school and you will get full-time integration aids.

You change from one into the non-government sector and that funding is taken away from the child and they are left without an integration aid full-time. I believe under the DDA that these children should be getting some protection. There should be something there to say, "Look, we have this equality in funding." That's my main bitch.

MS McKENZIE: Sounds fair enough to me.

MRS OWENS: We have had the "bitch" a few times now.

MS McKENZIE: Numbers, that's right. You've got a good bit of a chorus going there, I think.

MRS OWENS: The independent schools, I think, have done a very, very good job of bringing the differential funding arrangements to our attention and we'll be hearing, as you know, later today from the Association of Independent Schools in Victoria, when I think your grand daughter is going to come along.

MR BYRNES: Yes, she will be here.

MRS OWENS: So we have been getting, I think, a very good feeling for the funding, the government funding arrangements.

MR BYRNES: Yes. Even our Disability Service Act here in Victoria has got principles and standards in it that say these children should get the same services and everything as everyone else in the community but, still and all, the state government once again lets us down. They just say, "Students with disabilities in independent schools is the Commonwealth government's problem," and pass it off like that. The Victorian Department of Education's answer is, "We fund the school, not the child," and you're running into all these sorts of barriers. I can't understand the Victorian government. They are citizens here of Victoria and their parents pay their taxes. Just to say that it's the Commonwealth's problem - I believe that's not right. That's just hiding behind bushes.

MS McKENZIE: Yes, and it makes it hard, doesn't it? If you want to send your child to an independent school, you might sometimes almost be forced to send the child to a government school because of the different funding.

MR BYRNES: That's it. I have spoken to lots of parents and they have even kept their children back a year or two in a government school, even though they wanted to send them to an independent school, hoping that they would eventually get the funding to be able to have an integration aid at the school. They hold their children back from time to time. The thing is, when the child - I'll go back to my grand daughter, Emma.

When she started primary school she went to a government school and she was assessed by the Education Department as needing a full-time integration aid, speech therapy, occupational therapy, which she got. When she finished primary school the choice was to go to a Christian school, and she lost 99 per cent of that funding. The government is saying, "Yes, we're responsible over here in this sector but, once you cross the white line, we're not responsible for you any more, even though you're a disabled citizen, Australian citizen." To me, it just doesn't completely make sense. I think the whole solution for this problem - they've got it in Great Britain and America, Canada - is individualised funding.

MS McKENZIE: So you take it wherever you go - whatever school you go to?

MR BYRNES: When you start your primary school you - there are different ways it can be run, but if they come to you as a parent and say, "All right. Your child has got cerebral palsy, got no mobility, self-care. We'll sit down and discuss how much a year do you want to get all these services and facilities?" and if you sat down and said, "This is going to cost us X amount of dollars for a full-time integration aid, which is X amount of hours a week, that'll be $25,000 a year plus speech therapy, occupational therapy, another $5000 a year. We need $30,000."

Now, that money is allocated to the parents, or the child's minder. They go into an agreement. They have an agreement with, say, for instance, the Department of Human Services here, and they must be accountable on how that money is spent. They can review it in three months, six months or 12 months. It also gives the children with the disabilities and their parents a chance to choose their own services and what they want. It gives the child, as she gets older - like say around 13 or 14 - to make her own decisions.

She may not like that person she is having physiotherapy with and she might say to mum, "I don't like her," but mum says, "You've got to go there because that's the one I take you to," but then the child, if she's controlling that money, she can say - or he can say - "I wish to change and we have got the funding." They have got control of their life a little bit more and they become more responsible for themselves and it helps them to grow and come into the community, I believe. I believe it's a good thing. Thankfully, I believe that the Department of Human Services are looking at it because they're having a review into their Disability Services Act and everything in the next week or so and they're starting on that. I believe that would stop all this funding business of taking it off you when you go from a government to a non-government school.

MS McKENZIE: And going to the non-government school, who then is going to make up the shortfall in funding?

MR BYRNES: Yes. The government - which they know they won't do, but if all the independent schools tomorrow were to close down and say, "Right, we're finished," where would the government put all these students, because they haven't got the facilities to take them at the moment and probably never would have them. It would cost them millions of dollars. I know the wheels turn very slowly in government, but seven years to get standards through is just a little bit too long.

MRS OWENS: Before we get on to standards, just coming back to the idea of the dollars following the child, I have to say I am quite attracted to that sort of approach, but even with the Department of Human Services review you've still got an issue: they'll only be able to influence what they are spending themselves, and some of these dollars are Commonwealth dollars.

MR BYRNES: Yes.

MRS OWENS: Somehow the thought process needs to bring together the state and Commonwealth dollars and say, "How best can we fund those kids to go through the schooling system?" It needs to be thought of as a whole - - -

MS McKENZIE: There's got to be some integration of funding.

MR BYRNES: Yes.

MRS OWENS: I have been thinking aloud with some of the other independent schools associations about this idea and it may be possible to have some sort of classification system for kids, and your grand daughter would fall into a particular classification, which would allow for X number of dollars for that child to go to school for a particular year.

MR BYRNES: Yes.

MRS OWENS: It would need to be reviewed from time to time, depending on what year she's in and whether she's in primary school or secondary school - early secondary school or later secondary school - because the resource requirements may differ over time.

MR BYRNES: Yes, that's true.

MRS OWENS: I am quite convinced that it would be possible to develop something logical. It's just a matter of bringing the Commonwealth and the state governments together to work this one through, and that's where you potentially could have some problems.

MR BYRNES: Yes.

MRS OWENS: So there is that issue about distribution of funding and who is paying for what and kids in government schools getting more. The other issue is the level of funding, how much money is made available for your grand daughter or for other kids with disabilities.

MR BYRNES: Yes.

MRS OWENS: That brings us to the standards because, if we ever get to a point where the standards are accepted, potentially the level of funds that will be required will be much greater because the standards are dictating a certain level of service. We've had some case studies presented to us by the Independent Schools Association and we talked to the national association in Canberra and they did a few calculations for different types of kids and what the resource requirements would be if the standards were introduced, so that raises another big issue.

MR BYRNES: Yes. As you say, the Commonwealth and the state have got together, but then the Commonwealth turn around and say their role in education is complementary to the states and territories, which have primary responsibility for the provision of schooling in their represented states. What they're saying is, "Here's your Commonwealth money. You sort it out."

MRS OWENS: Yes.

MR BYRNES: If they're handing over X amount of dollars and the states - say for Victoria - want to do that type of funding, I don't see how it is going to affect the Commonwealth government because they are saying they've got a complementary whatsaname in it. They have to have some guidelines, which are not great and, to me, I don't think that should be a great issue if they are only - providing that they hand over, you know, a sufficient amount of money to cover it, and that's it. Once they hand over the money they're saying they're only complementary and they're backing out of it after that, and selected states and territories - I think once again it all comes down to cash. It all comes down to cash.

MRS OWENS: Yes.

MR BYRNES: As it came out of the state employment workplace relations education - you know, the Senate highlighted it there - that the real concern of states is to link the cost of their obligations with respect to standards.

MS McKENZIE: What views have you got about mainstream education for people like your grand daughter?

MR BYRNES: I beg your pardon?

MS McKENZIE: Mainstream education for people like your grand daughter.

MR BYRNES: Great. It was very, very good. She went through with flying colours because she had her full-time aid there, which you know when an aid - she just gets her books out and things out, ready for her. See, we've got a child that can't even take herself to the toilet, and if she wants books over there because the subject has changed, the aids go and do that for her. She was able to use her Hart walker all the time at school because she had an aid there to put her in and let her go, and that was one of the greatest things for her because of her exercise and everything - she could use her Hart walker with a full-time aid. She went through with flying colours. She just whizzed through it. Intellectually she's brilliant. She's a brilliant child. High scores and all the passes and everything. She done the exam to go into the Christian college. Wasn't allowed to have an aid or anyone to assist her there. She only completed 85 per cent of it because of the time barrier and she finished in the top 10 children.

MS McKENZIE: They wouldn't give her additional time to do the exam?

MR BYRNES: She coped with it and got through, and that's the greatest thing. Our greatest thing is the problems with her health because of her age. She turns 14 next year - next month, I'm sorry - coming to puberty. What happens if the big thing happens while she's at school and she's got no aid? Her mother has to give up part of her work to go there and help, so she's got somebody. This is the case, but I've written probably to every politician, state and Commonwealth, but nobody seems to help, even though you say we've got this Disability Services Act here and it has got principles and standards in it, but principles and standards - do they have to abide by them? It doesn't seem as though they do, politicians.

MS McKENZIE: What about getting her books for her and so on in the Christian school? Who is going to help with that?

MR BYRNES: A lot of the children there do it for her. They'll get up and do it. There are a few of them there who went through primary school with her, and they'll just say, "Oh, we'll get it for you, Emma," and go and get her lunch and all that sort of thing. She never even - as I say, she had no mobility, she can't move herself around in the wheelchair, and the children used to push her around when she first started there for the first six months, and then the students and the teachers worked together and raised funds and bought her an electric wheelchair, so that she'd have more mobility. We couldn't even get her an electric wheelchair through the Disability Services because there was such a waiting list, they said.

MS McKENZIE: So for that there was a very long waiting list, was there?

MR BYRNES: Yes. So that's helped her greatly. But she's not getting the exercise at school that she used to, as I say, with the Hart walker. She just loved the Hart walker because she could go out in the schoolyard and be involved with the children. They used to have her - not so much playing netball or anything, but she used to be scorer for them, scorer for the cricket, scorer for the football. They involved her in everything. They were very good to her. It's brought a lot of the children awareness to disabilities at the school. They'd never had a child with a disability at Flinders before.

MS McKENZIE: In the primary or in the secondary?

MR BYRNES: In the secondary.

MRS OWENS: So it's good for the school as well.

MR BYRNES: Yes, and they're so good to her, and they've realised it, and they all help and everything, and it's brought a great awareness to them and a lot of their parents. A lot of the parents allow them to take her home and everything, even though she's got to be toileted and everything. They reckon it's great. They reckon it's good for their kids, because they've learnt to appreciate what they've got, how well they can walk and run and do things.

MRS OWENS: How much time does her mother spend there with her?

MR BYRNES: Two mornings a week, I think, which is probably about three hours of a morning.

MRS OWENS: But, I mean, as you say, when she reaches puberty, the mother is going to have be there quite a lot more.

MR BYRNES: Well, yes, that's it. It's a thing that teachers can't do and students can't do, and mother will probably have to be there at that time. This is the thing, the aid will be there for three hours of a morning or afternoon, whenever she comes, but she gets that aid for three hours a day - I think it works out about 15 hours a week or something. The school pays for part of it out of the funds, I think - instead of a recurrent grant as they get to help them through the school - I think they use a lot of that so that they can partly fund the integration aid. $3000 a year is all she gets for an integration aid from the Commonwealth government.

MRS OWENS: How many hours does that pay for?

MR BYRNES: Well, as I say, she gets about 15 hours a week, and I believe the school is putting more money into it.

MS McKENZIE: So it actually will cost more than 3000 for that?

MR BYRNES: Yes. With her speech therapy, as I quoted there, it costs $60 a session. The state government allows $18 an hour. We've now found a place in Frankston where they take her there. The parents pay for it, but they get so much back off of Medicare or through their health system, and that sort of gets us through and saves her a little bit - saves the school a little bit of money, which goes towards helping her with her physiotherapy and occupational therapy. So it's all sort of juggled.

MRS OWENS: To the extent that the school is partly subsidising, say, the integration aid, that's really coming out of the fees of all the other parents?

MR BYRNES: Yes, out of the school funds.

MRS OWENS: Do the other parents react towards that?

MR BYRNES: No. The school committee and everything is quite accepting. The only thing they say is that they're sorry they can't take more children like Emma at the school, but they have only got the funds to look after her at the moment. If they got two or three others in the same situation, they just wouldn't know what they'd do, because they can't really refuse them.

MRS OWENS: Well, they may have to either refuse them - - -

MR BYRNES: Yes, because they would come under - - -

MRS OWENS: - - - or take them on and then put the fees up.

MR BYRNES: - - - unjustifiable hardship, yes.

MRS OWENS: Yes. I presume the fees aren't that high at this school.

MR BYRNES: No. It's not a rich private school or anything like that; they're not high. The reason why Emma in the first instance - there was plenty of schools around, but they took her around to all of them, and it was a small school with only about 500 students, it suited her, she felt safe there because her friends from the other school were there, and plus she wanted to study theology - she's Christian upbringing, and she wanted to study theology, and that was her main reason, that she wanted to study - and that's the reason. As I say in the submission, they're not being discriminated against for their disability, but they're being discriminated against for their right of choice, to choose a school that they wish to go to.

MRS OWENS: It just means that any other child that is going to that school without a disability, they have got the choice - a full choice, whereas Emma's choice is a constrained choice.

MR BYRNES: Yes, been penalised. That's about all that I can tell you about it. That's my little gripe.

MS McKENZIE: Well, it's a very good submission.

MR BYRNES: Thank you very much.

MS McKENZIE: What you've told us is really very helpful as well.

MR BYRNES: Thank you for allowing me to speak on it.

MS McKENZIE: Thank you very much.

MRS OWENS: We will, as I said, be talking to the association this afternoon as well, but I think it's really good to get this issue out from the perspective of the family - one of the children. I think just getting that perspective is very valuable.

MR BYRNES: Yes. I'm glad you feel that way. Thank you very much.

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

MRS OWENS: The next participant this morning is the Intellectual Disability Review Panel. Welcome to these hearings. Could you please give your name and your position with the panel for the transcript.

MS TAIT: Thank you. My name is Sue Tait and I'm the president of the Intellectual Disability Review Panel.

MRS OWENS: Thank you, and thank you for your submission. I'll hand over to you. You're going to expand on some of the matters raised in that submission.

MS TAIT: Yes. Thank you. I guess my primary interest in the Disability Discrimination Act dates back for 10 years when I was involved in writing a user guide for the DDA and a manual for advocates. At that time it was a privileged position to be in to, if you like, have the untapped potential of the DDA before us, and so the enthusiasm of the peak bodies representing people with disability, people with disability themselves, and I guess people like myself who - I generally would describe myself as a human rights lawyer, so not with a particular interest in disability until I was engaged to write about the DDA and to provide information about how to use it in lay terms.

I guess my experience of the practice of the DDA is somewhat limited, although I worked for four years as a community lawyer in a legal service that worked only for people with disability, and we didn't target discrimination issues because of an already existing service here that does that, but we did often engage in discussions with our colleagues there, so I had a bit of up-to-date stuff that happened, but for the last three and a half years in my current position, I haven't really had very much to do with discrimination issues directly, although in my capacity I'm also on the Victorian Disability Advisory Council, so I get to see issues that relate to people other than people with intellectual disabilities.

So that the broad-brush background, and I guess I'd want to emphasise that I think that the DDA needs to be seen as part of a package of reform primarily. I don't know whether or not you want to expand on some of the points that I made in the outline of my submission, but just perhaps to I think understand that, the DDA wasn't the only thing happening at that time. There was the Commonwealth-State Disability Agreement. I think there was a clear agenda being run from the Commonwealth about improving issues about citizenship and removing barriers for people with disability.

I guess in Victoria in my own area now, in the Intellectually Disabled Persons Services Act - Victoria is one of two jurisdictions internationally that has a special act for people with intellectual disability, a specific act, and that was really brought about by a clear perception of the human rights issues for people who had been incarcerated in institutions, and the act as it was drafted in 1986 was firmly embedded in a rights framework and in a framework that had shifted from a medical model of intellectual disability into a social model of disability, and I think that also impacted on other areas - in other words, other areas of people with disability.

So I think that from your perspective to isolate the benefits particularly for the DDA is quite difficult because I guess, by way of example, at the legal service I used to work at and in community education with service providers, particularly service providers who work only with people with disability, I would often say to them that if they were having difficulty in engaging community access with people they were supporting then they should just remind the shopkeepers or the yoga teachers or the aerobics classes that they had responsibilities under DDA not to discriminate, and in fact positively to make adjustments that might be necessary for enabling people with, you know, cerebral palsy to participate in aerobics classes, that sort of thing.

To isolate the DDA I think is impossible in that measure because there was nothing that was ever able to be measured by way of a complaint or anything like that, but the spirit of the DDA is something that I think in most of the community education work I do - and I do a fair bit and have done a fair bit - has always been a component.

I think the other issues about measuring the benefits for people with disability and the community at large of the anti-discrimination nature of the DDA is quite difficult because of the historic isolation and segregation of people with disability, so the barriers to community attitudes I think have been much more pervasive and somewhat different from other areas of discrimination. Most people, unless they have a family connection or a family friend, would not have met or had friends with disabilities generally, and so some of the barriers to those community attitudes that the DDA tries to address - when I have taught people about that or trained people about the DDA, they've always raised issues about safety, "We've all got duties of care here" - a very sort of ingrained, paternalistic model - you know, "How can you say that you would be wanting people with cerebral palsy to do tree-lopping in a TAFE course?" and the theory is that you would want to do it very slowly and with lots of rubber trees, but why would a person who wanted to do that - why would we limit ourselves and limit our imagination about that if that's what the person wanted to do, and if we are truly about human rights, then we're on about encouraging people to explore themselves to be the person they want to be, so long as they don't harm others.

I guess the other thing about the general issue for the commission's inquiry is that in relation to the Disability Discrimination Act, people with disability are not like people of a particular race or people of a particular culture, that from my experience, the common trait people with disability share will generally be limited to their experience of discrimination. In other words, they will generally only share the experience of barriers to living lives that people without disability live. So I think that's one of the comments that I would make about the impact of the DDA. If I think about not having a disability myself or not identifying as having a disability myself, in 10 years we can see ramps and we can see in lifts Braille stops.

The physical changes to our society are there in relation to I think particularly issues about mobility and access for people with mobility impairments, and I think to an increasing extent people with vision impairment and people with hearing impairment, that they're clear, physical, concrete examples we can see, if you like, in the difference between now and then. But some of the more hidden disabilities or some of the disabilities that impact in I think particularly cognitive areas - I don't know that there has been an impact of the DDA, and I guess I'll go to that a bit later.

But I think that one of the problems with the reform package that was proposed and one of the ongoing gaps that we have that the DDA really can't address but that government needs to address is that true cost of disability, that true sense - well, for example, I now work in premises that are shared by other independent statutory authorities, funded through Human Services. One of my colleagues who works at the Disability Advisory Council is deaf and uses auslan interpreters, and last year we were thinking about having a floor Christmas party and we were all going to socialise, and he was not able to participate in that socialisation except on a one-to-one basis.

I should say in the interim some of us have tried to learn auslan in the workplace, without much success, really. But should he have to pay for that participation in something that all of us take for granted, the office Christmas party, for those of us that work?

MRS OWENS: We might just break for a sec.

MRS OWENS: Okay, we may resume. We were talking Christmas parties, and should you have to pay to attend the Christmas party.

MS TAIT: That's right. Who should pay? I guess in the sense that I know that lots of disability groups are asking for there to be recognition of the cost of disability, and I think that is a fundamental aspect to some of the issues raised by the Productivity Commission in relation to costs currently that must be borne by individuals, either individual employers or individual respondents in DDA complaints, rather than a recognition that this is a piece of government legislation.

This is a government commitment to removing barriers for people with disabilities, and frankly, the government have to pay for that. It's they who are wanting - in response to improving our society and community, it's they who are wanting to acknowledge the equal rights of people with disabilities, and in the same way that the government accepts responsibility to pay basic health for us, and basic education for us, and basic transport for us, I think it needs to pay, if you like, for the leg up, or the adjustments that people who have a disability need for those basic fundamental expressions of their sense of belonging to our community, them being part of our community. That's, if you like, what I see to be the bigger picture issues for the DDA; things that the commission need to have in mind, if you're thinking about the DDA specifically. In relation to some of the questions raised in your discussion paper I really only want to address a couple. That's partly because I only had time to - - -

MRS OWENS: That's fine, because you've just raised a really important issue which I'd like to come back to, which is who should pay? We've been asking quite a few people that. We could do it now before you go on to those. Do you want to finish first?

MS TAIT: The three issues raised in the discussion paper about the definition of disability in the act, including the fact that imputed disability is there and the breadth of the definition is clearly intended not so much to reposit the issue with the individual, but to say that it's the way in which others treat the individual, because of the trait or the perceived trait, and so that, in removing that prejudice or discrimination or the - and I mean that in a non - if you can use "prejudice" in a non-pejorative word, the prejudging of individuals about what they can and can't do because of a particular disability, which may be paternalistic, or it may be for hidden disabilities beyond a person's ability.

But if the sense is to eliminate that prejudging then I think it's about changing the society, not changing the person, and it's changing the attitude that people have to these traits, not about the traits themselves. I guess that broad definition is now - Australia led the world a little bit in some of the WHO classifications of disability now which is much more clearly repositing disability as a social model, not just a medical model, not just something about the person. So that's all I can say about the definition.

In relation to competition, I am not up to date with the case law on unjustifiable hardship, but I do recall looking it up in the dictionary when we wrote our manual and thinking unjustifiable hardship should be the great leveller in relation to competition. The cost of providing a ramp for a Safeway supermarket is hardly ever an unjustifiable hardship but the cost of providing a ramp for a milk bar owner that only has one person who uses a wheelchair may well be an unjustifiable hardship. I guess I would be saying that the cost of government in providing access and accessible services and making adjustments for people with disability should hardly ever be an unjustifiable hardship but that small businesses could well rely on that, and appropriately rely on that.

I guess the other thing that I would say about competition and particularly in the area of employment and the area of commercial interests - and I've done training for employers on this issue about the fact that if you take the catchcry of modern business, it is about rewarding innovation and being able to respond to individual needs, and if there is anything you can say about employees who have a disability, they generally are the most innovative amongst many in relation to the way they've made their own adaptations to the barriers they have faced. So being able to learn from disability - I don't want to sound like Pollyanna, but I firmly believe that.

I worked with a woman who was on a committee of management and she had an intellectual disability and I was trying to explain something to her and she said, "That's just set off a butterfly in my brain." Now, if that's not the most perfect way to describe an idea - so I guess that's the sense that we are all different, and we all benefit from learning from each other; that idea of being able to capture that learning and using it as a competitive edge. Again, I don't want to talk about my deaf colleague all the time, but we were talking about how it would be if his bank was required to provide an auslan interpreter for him. He was saying surely that would be an unjustifiable hardship and I said it may well be, "But if your bank was providing an auslan interpreter how many of your mates in the deaf community - - -"

MRS OWENS: Might go to that bank.

MS TAIT: Yes. In the same way that banks now advertise languages other than English with tellers - speaking tellers - shouldn't the disability community be given that competitive edge, appropriately to maybe a disability accessible restaurant guide in the same way smokers have done it. That sort of thing. I guess that competition issue is dealt well with, within the current boundaries of the act. I'm conscious of the time, but to get to some of the problems, and I know that I've seen some of the submissions that you've already had in relation to the issue about it being a complaints driven process, so I won't talk about the burden of a person having to complain when they've got the disability themselves.

I'll just talk about my work now. We act as if we are an ombudsman for people with intellectual disability. I started my job on 1 January in the year 2000 and at that stage there had been zero complaints. So there are 4600 people who receive disability services who are identified by the service providers as having no effective communication. So those people find it very hard to complain. There are 17,000 people altogether who used disability services and yet we had received none in the first six months of the financial year that I started this job.

MS McKENZIE: When you say "disability service" you mean Intellectual Disability Services?

MS TAIT: No, I mean the whole of disability - - -

MS McKENZIE: The whole range?

MS TAIT: The whole range of disability funded services. It is only people with intellectual disability, or their families, that can complain to us, and the great majority of that 17,000 - I think 14,000 - are identified as having an intellectual disability. But in talking to people about why nobody complains - and, by the way, I could say we had a 300 per cent increase in productivity in the first six months I was in the job, because we had three. There are real issues about complaining. There are real issues about complaining, particularly complaining for regular contacts - so complaining about your GP, complaining about your school, complaining about your church or your club, if you want to remain in it, is a real issue, I think, and a real issue for people who - particularly I know that the fact that associates are included as complainants is a very good thing for many people, but primarily it's for people without cognitive impairment who benefit from that - you know, friends who go to restaurants with friends in wheelchairs, that sort of thing.

But for friends or family members in particular of people with cognitive impairment, the reliance on them when they struggle with really quite significant attitudinal discrimination as well as the physical barriers I think is difficult. I would be really encouraging any - if there is, if you like, consideration of reform within the current framework of the DDA or recommending reform within the current framework of the DDA, I think really bringing back the self-initiated, the ability to - for the commission to initiate its own inquiries, is really important.

The standards: frankly I've always had a problem with the standards and that's been brought about in seeing how many people spend so much time to come up with something that not everybody is happy with. I think the Americans with disability did a lot of work on good standards - good-good, you know - and continue to do a lot of work particularly in relation to architectural issues and stuff. Those should be considered to be the benchmarks against which we lever for better issues.

I think there are problems with action plans, too, in that the only benefit of action plans is by involving people with disabilities about them being able to work with services or employees or employers about how the adjustments need to be made.

MS McKENZIE: Otherwise you mean it turns out to be a, "We decide what's best for you" approach?

MS TAIT: Yes, and it's the same - you know, they become - the ISO sort of standards where you tick the box and you've done everything right, but actually there's not been any opportunity for exchange and integration. I didn't really have much to do with people with disability until I was involved in the work for HREOC, and I remember after we launched our manual saying to Elizabeth Hastings that we should go for a drink and she said, "That would be great except there are no pubs that are accessible within six K of the CBD of Sydney," and until you've got that personal exchange then the paper doesn't - the paper doesn't involve, so you need to actively involve people with disability in the relationships and the discussion and the development of the plans.

MS McKENZIE: Can I just go back to standards for a second. Would you then say that there shouldn't be standards at all, that the act should simply be relied on, or should they somehow be adopting some of the American standards?

MS TAIT: I frankly don't like standards, and that's not to say that maybe the issue of guidelines or practice statements - or policies even - that are constantly reviewed - that might be an appropriate thing from HREOC. I know that they talk about on their web site frequently asked questions and those sorts of things as being a good way - I think using the benchmarks from the states as, if you like, examples of best practice, but not locking them in as they have been locked in as regulations. My understanding is that they engage enormous amounts of resources in time, hardly any of which is actually reducing discrimination for people.

It's a process issue which I don't think produces much benefit. The end result in transport may be a nice plan of attack, but it's really much more an action plan than the standards - my understanding of them anyway. They're really about an action plan for the transport industry, not standards per se. I think that that's a better role for HREOC and it's a better role for some of the activities that happen around standards, engaging with industries about educating them and using different sorts of ways for them to meet, if you like, in a process way, the steps to providing, if you like, the level playing field.

MRS OWENS: We have on the other hand heard from others who have said, "Well, standards are important" - and you probably heard these arguments - "because they do reduce the level of uncertainty out there, and we'd like to see a standard because otherwise we don't really quite know what we have to do to achieve the expectations," and others have said that by having standards you reduce the potential for individual complaints. If the employers, or whoever, abide by the standards, then there are no grounds for complaints. That could be a good thing or a bad thing.

MS TAIT: Yes.

MRS OWENS: So we have heard the other side, the story which says standards are a useful device.

MS TAIT: I just wonder whether or not guidelines wouldn't serve that, or better education, like giving particular areas of industry or particular industries information or access to information about what is happening, if you like, by best practice. The problem with the standards is the minimisation, so that seems to - my understanding about what quality assurance is about continually reviewing, continually aiming higher for best practice. If people say it's good to be able to predict what we have to do, I still think that is actually quite an anti-competitive approach to it. We shouldn't be predicting what we have to do. We should be trying to do what we want to do as well as we can.

MS McKENZIE: And over time it's true: best practice will change.

MS TAIT: Yes.

MS McKENZIE: I mean, it could possibly be that many, many years ago, people might have said that the best practice as far as a child with a disability was concerned was to segregate them within a special school.

MS TAIT: Yes.

MS McKENZIE: Whereas now best practice is entirely different.

MS TAIT: That's right.

MS McKENZIE: And if standards are going to take so long to change, if they are going to take as long to change as they did to develop, it's going to be very hard for them to keep up with those kinds of changes.

MS TAIT: I think so, particularly with the information internationally we have access to now is so rapidly growing - you know, it's so overwhelming that I think locking into standards with a regulatory power is minimal. The other thing is the notion of removing discrimination in my view is about creating a more diverse inclusive society. It's all right to have standards for opening lifts, but what happens if you've got a very fat person in a wheelchair? We are changing. Shouldn't we be saying, "The question is, what is the adjustment we need to make here?" That's the first question. Then, is this adjustment an unjustifiable hardship?

They should be the key questions and, if there are enough people for whom making the adjustment is necessary, then you know that might be the way in which adjustments happen. These might be examples of practice. This the way in which a good employer will provide for a hearing-impaired employee. There is some discussion about reasonable adjustments. HREOC has invented the reasonableness, as you have identified in your discussion paper, and I think dangerously so.

If there is a student who says they have a hearing impairment and that they would benefit in a university lecture by having an auslan interpreter, notes beforehand, and a note taker, all of which are costly, where are we to say which of these adjustments is reasonable and which of them aren't, and why the package might not all be reasonable? If we take the notes beforehand, every student will benefit from that. If we take the notes beforehand and a note taker, then a student doesn't need to come to the lectures but will miss out on any interchange. The question should be, for this particular student in this particular course, is this an unjustifiable hardship, in my humble opinion.

MRS OWENS: Yes.

MS TAIT: I guess the other - because I am conscious of the time - problem I see with the DDA really, really significantly is the special measures exemption, and the HREOC site doesn't actually describe where that exemption was used in the equivalent state legislation in Victoria, but the special measures exemption was used to completely excise - - -

MS McKENZIE: You're thinking of the Collier case?

MS TAIT: I'm thinking of the Collier case, That's right.

MRS OWENS: What was that case?

MS McKENZIE: The Collier case very briefly was - and, Sue, you can correct me because it's a while ago - a case where there was a question of whether people with intellectual disabilities should be transferred to a community based accommodation or remain in the institutional setting, and a discrimination complaint was brought in respect of those people who had been told that they would remain in an institutional setting, and who wanted to go into community based accommodation.

Without going into the details of how the discrimination case was spelt out - because it was quite a tricky matter - the Equal Opportunity Act has a similar section to the special measures exemption - and, after various decisions, some of which were mine, the matter went on appeal, and what the Supreme Court said was that when that section speaks about special services designed to meet the special needs of people with particular attributes, people with intellectual disabilities - as long as you could say that those services or those decisions were designed to meet those needs, that took the entire decision out of the ambit of the Equal Opportunity Act in Victoria. You didn't have to look at whether the design was reasonable or the decisions were reasonable. You just had to look at whether, as far as the decision is concerned, the decision-maker had designed the decision to do that particular thing. If that was the case then the matter went out of the scope of the Equal Opportunity Act.

MS TAIT: Yes, and I think that the current - well, I know that the advice when I was working in the legal service was that it was very, very difficult to bring discrimination claims on behalf of people who lived - or who received specialist services.

MS McKENZIE: For that very reason.

MS TAIT: That's right, and the comparator issue, as well: how can you compare how Third World conditions exist at Kew Cottages for people with intellectual disability when there aren't any other people who live like that? I think the notion that there is, if you like, a human rights issue for people with disability that's currently not addressed by the DDA - that is, the human rights of people who use specialist services and what's happening in those special services. I can talk about particularly the accommodation, but it's not limited to that, and I'm aware of employment programs.

There was one employment program that was for people with a broad range of disabilities, which participants paid a fee to enter. I think the annual book said there had been 15,000 paid in participant fees, 20,000 paid out in wages to the participants. The organisation had assets of $600,000, and the paid workers were on minimum wages of 40,000 plus. Now, this was a special supported employment program for people where their business was actually competitively tendering with other businesses, and it frankly was just exploitation flavour. The fact that people who work in supported employment services now - or the old sheltered workshops - are not entitled to WorkCover, not entitled to sick leave, not entitled to retirement benefits. They will have worked full weeks for $1 an hour, and the fact that those people - really it breached the fundamental human rights issues in employment, but there's nobody nationally, federally, with, if you like, a watchdog role in that area, and that's a huge gap and it's a gap that I think is reciprocated at state level as well.

MRS OWENS: I suppose there are other ways you can address that issue, and we'll be talking to others later this week about this issue, about business services and what you could do say within the awards system and so on, but that particular exemption for Disability Services, I think was put in for the right reasons, and that was to protect those services which potentially are beneficial services for people. I mean, it's a matter of being able to have a business service so you can say, "We are going to employ just people with disabilities," so somebody else doesn't come along and say, "Well, I want to be able to get a job in that place." I don't know why they would want to for $1.70 an hour, quite frankly, but it's meant to be there so that you can provide special services that other people in the community don't get access to.

MS TAIT: Yes.

MRS OWENS: There's a bit of a dilemma there.

MS TAIT: There is a dilemma, and I don't know that I've got the answer to that dilemma, except it seems to me that as soon as you start talking specialist and you start talking about people who might be disenfranchised or more vulnerable, specialists become segregated and isolated very quickly, and the role of specialist support services should be to do themselves out of business - should be about building bridges across to the mainstream - you know, to the level playing field - but they become an industry in themselves, in my view, and I guess now in my current position I see that area as being significantly exploited with the rights of people who have a disability. The more vulnerable, the more exploited. I mean that not only in the employment area, but in the housing area, in the accommodation area and in access to medical services, access to training, access to transport.

MRS OWENS: But there may be other areas where you might say that some people with disabilities might, on an ongoing basis, need special arrangements. Some people don't necessarily want to or need to be integrated into the general schooling system, mainstream schools. There may be a case to still have some special arrangements, special schooling for some people. I don't know - maybe there's not. But it might be that choice is important for some families and for some kids.

MS TAIT: Yes.

MRS OWENS: And you don't want to deny people that choice, or the ability to have special arrangements. I take your point about maybe getting to a point in society where you don't need some of these services, but in the meantime, we probably still do in some areas. You need something to protect that, don't you?

MS TAIT: That's right, and I guess it comes back to that special measures exemption in the DDA; that if you had HREOC with a watchdog role over that area, that would go some way to addressing what are some of my concerns in some of those areas, so that you have a human rights perspective about - are we treating these people in this specialist service better? If we are clearly treating them better than - if we are giving them the leg up here, then clearly that is consistent with the DDA. But if by ordinary common human rights and commonsense what we're doing is disadvantaging, through this special measure, then there needs to be a watchdog so you can't do that.

MRS OWENS: There are a heap of issues we could be discussing with you at this stage, but there is just this question that you did touch on about the complaints process and how few complaints there had been, or zero complaints when you got into your current job.

MS TAIT: Yes.

MRS OWENS: That is one of the issues that we are obviously addressing, the imbalance between the access of the system between different groups in our community. People with intellectual disabilities, it would appear to us, do have greater problems of understanding their rights, being able to make complaints, just generally understanding how they can use the system.

MS McKENZIE: What way might there be of sorting this out, based on your own experience of complaints under your framework?

MRS OWENS: You talked about HREOC having the power to initiate complaints, but does that get you all the way there?

MS TAIT: I think it does if you say that they can initiate complaints through the public inquiry process.

MS McKENZIE: So systemic matters.

MS TAIT: Yes, so that particularly if you give them some - wherever there are people with disabilities, then we can step in here and have a look at what is happening in relation to human rights, compared to citizens of the same age.

MRS OWENS: But there may be individual complaints. You might find somebody who is being harassed, say, in their accommodation unit or whatever. It's very hard for that individual to be able to get outside to tell people - it might be one of the staff members.

MS TAIT: Yes. I guess that idea of being able to have anonymous complaints. There's no other way of doing it. We get complaints from staff members, but we guarantee - I can't say the word - anonymity. So we will go to quite diverse measures to make sure that they're not able to be taken, and that's despite this whistleblowers legislation, but I think if you made it clear that the commission could accept anonymous complaints, subject to them being satisfied that the complaint wasn't vexatious, for example, and use that as well as the ability to initiate, so that you have disgruntled - there is some discretion about just not targeting where a disgruntled worker might be, but encouraging people like, for example, community visitors. I don't know what exists in other states but our current legislation is being reformed and that is what we would be asking for, the ability to respond, either self-initiated or respond to anonymous complaints to take positive inquiry, like an inquisitorial approach to what is happening - whether a group of people may be having their fundamental rights being abused.

MS McKENZIE: So use that information to initiate some of the steps, whether it's a complaint or - - -

MS TAIT: Yes, that's right, so the commission being able to inform itself in any way it liked, including accepting anonymous complaints. There is stuff about natural justice and ability to waive the Rules of Evidence. I don't think inquisitorial bodies have got quite that, in this jurisdiction anyway, stepping into the playing field and informing themselves. Those waiving of the Rules of Evidence tend to be waiving hearsay and stuff like that rather than some, if you like - if a person can't be - the adjustments that need to happen through the process, where a person is cognitively impaired or not able to assert themselves - in fact, you don't need to necessarily tell the complainant. It's quite a complex issue, but how much natural justice do you afford an eminently powerful person like Alan Bond and his right to remain silent, compared to what might be - that's not a good example, I'm sorry, but in balancing the hearing process I think that the commission has the right to inform itself and not necessarily identify who the accused or accuser may be, so to take anonymous complaints.

MS McKENZIE: The only other question I was going to ask you was going back to this cost of discrimination or cost of reasonable adjustments issue. You said earlier, and rightly, that at the moment the cost is on the respondent if there is a successful case. How would you change that, if you would change it at all?

MS TAIT: If I had a complete and absolute magic wand I would be suggesting that we should be talking about something like the mobility allowance, something that was, if you like, a fund - a Commonwealth fund - in the same way that the pharmaceutical benefits fund is a fund, or the PAPD fund is a fund; that there is a fund which, subject to assessment and not too bureaucratic, entitles a person to let's say, you know, to apply for the cost of their disability. You could cap it, but it's that sense that we have a Medicare system about health, we have a free - or we have an education system about education. Shouldn't there be a publicly funded source of adjustments, rather than individual employers or transport - it's part of the infrastructure of our community that I think vests appropriately with government. It is a government act.

MRS OWENS: You've just answered the question I was going to ask you earlier. It was a similar question, so I think we may finish now, unless there is anything further you wanted to add to what you've already said.

MS TAIT: No. Thank you very much for giving me the time.

MRS OWENS: You're raised so many really interesting issues that have been enormously helpful. Thank you. We'll just break for a minute.

MRS OWENS: We'll now resume. The next participant this afternoon is the Council for Equal Opportunity in Employment. Sorry for the slight delay in talking to you. Could you each give your name and your capacity in which you're appearing today for the transcript.

MS SQUIRCHUK: My name is Rohan Squirchuk. I'm the managing director of the Council for Equal Opportunity in Employment Ltd, which is a privately-funded employer association.

MRS OWENS: Thank you.

MR WHITEHOUSE: Hello. My name is John Whitehouse, employee relations and training manager for McDonalds.

MRS OWENS: Thank you, John.

MS BATCHELOR: And Cindy Batchelor, strategy adviser for the National Australia Bank.

MRS OWENS: Thank you. It's nice to have a couple of companies - employers represented here as well. I'm going to hand over to you to make your presentations. Who's going to go first?

MS SQUIRCHUK: If it's all right with you, I'll start, provide a bit of a background to the council and then hand on to John and Cindy, and obviously, as you said, if you've got any questions, just ask as we go.

MRS OWENS: Yes.

MS SQUIRCHUK: The Council for Equal Opportunity in Employment Ltd is a privately-funded employer association that was established by the Australian Chamber of Commerce and Industry and the Business Council of Australia in 1985. Initially its focus was in relation to the employment of women and, more recently, and in particular over the past 10 years, we've looked much more broadly at the area of inclusion of all the sectors of the community and, in particular, we've done a lot of work in the area of employment of people with a disability.

The council's involvement in the employment of people with a disability obviously moves not just in relation to its member organisations, which I'll talk about shortly, but also too in its staff, and as we were sitting up the back I worked out that we have a staff of 11 and 40 per cent of us have some form of long-term disability of one term or another, from sight impairment to intellectual and actually acquired brain injury and a number of other disabilities.

We've worked, for the time that I've been at the council, in the area of employment of people with a disability, and I thought I might start by providing a bit of a story about our own experience and some of the challenges that we've experienced in this area. The CRS came to the council a number of years ago and asked us to assist them in finding employment for a number of people who they'd had quite significant difficulties in placing in permanent employment, and one of them was a person with a hearing impairment. None of us had worked with a person with a significant hearing impairment before, and so we were going along trying to work out the best way forward with this.

Part of our commitment to the team as we get together every six months - what we call our journey sessions; we work out where we're going and try to get rid of unwanted baggage, if we can - and we were in a car and we were going out for dinner in the evening. I was driving, and the person with the hearing impairment was in the back of the car with two other people, and I'm obviously in the driver's seat with someone beside me, and I said, "Anna, put your seat belt on," and nothing happened. "Anna, put your seat belt on, because if you don't we're not going anywhere," and of course Anna couldn't hear me.

It's a very salutary lesson that we make a lot of assumptions that the way that we normally communicate with people is going to be effective in every situation, and what was interesting was both the people on either side of Anna waited for Anna to put her seat belt on, even though she couldn't hear me. I use that example really to say how important it is for us to recognise that with the best will in the world, and with all of the expertise that we like to think we have at the Council for Equal Opportunity, employment of difference, whether it's disability or someone of non-English-speaking background or any other kind of diversity, can be challenging.

The scope of the council's membership ranges from small employers with about 15 employees who actually provide service to people with a disability, through to two of the largest employers in Australia that we have present with us today. One of the things that we know at the council is that the employment of people with a disability raises many misconceptions amongst the population, and employers are no different. From the council's point of view, it's been one of the most difficult areas to make a difference with employers, and while we recognise - and I think the commission should recognise - that many employers have very high levels of goodwill and want to do the right thing, that in an increasingly competitive and global economy, with a sense of urgency to get things done, it often means that there are stereotypes about people with a disability by employers as being slow and less productive, and we need to counteract some of those stereotypes.

One of the areas where I have done a deal of work and which is dear to my heart is in the area of mental illness. I'm a lawyer member of the New South Wales Mental Health Review Tribunal, so I've done a lot of work in the area of mental illness, and it's quite clear to me, both in my role at the tribunal and at the council, that employers feel very high levels of anxiety about the employment of people with mental illness, and very low levels of perceived competency for dealing with the issues, and as our population is pressed to make all of us able to be participants in all aspects of life, that is likely to increase, and we have to find ways of decreasing the anxiety and increasing their perceived competency.

The ageing of the population and the decline in new entrants into the labour market means that Australia needs to be accessing and utilising a hundred per cent of the talent a hundred per cent of the time, and people with a disability hold a lot of our talent that isn't currently being used. I think that the passing of the Disability Discrimination Act and its gazetting really started the process of the recognition of issues for people with a disability in all aspects of life, but one of the things that I feel very strongly, and I did in fact petition the government on a number of occasions, is around their failure to appoint a dedicated disability discrimination commissioner after the completion of her term by Commissioner Hastings. I think it sends conflicting messages to the community and in particular to business regarding the importance of people with a disability and the whole area of the legislation.

Leading businesses recognise the importance of employment of people with a disability and the Disability Discrimination Act from not only the employment area but also in the area of service delivery, and today I have colleagues from McDonalds Australia and the National Australia Bank to talk about the work that they have done since the act has been in place. These organisations do it because they know it's good business, not just to feel good. So, with that, I'll hand over to John Whitehouse.

MRS OWENS: Thank you.

MR WHITEHOUSE: Thank you, Rohan. When writing some notes, I wasn't sure of what process to use, so I'll really just talk about what we do as a company and what we're aspiring to do. McDonalds in Australia have just over 56,000 employees. They are covered over about 730 restaurants. It's a very diverse workforce, with people starting at their first job, or university students, people who are looking at it for a career, also people that have maybe retired from the workforce and are looking for a part-time job. So it's a diverse workforce but it's again 56,000 employees, so it's a large workforce.

The approach to employee relations and HR that McDonalds has used in Australia is a very decentralised approach. In fact in my role I'm actually the only person in employee relations for the whole of Victoria. There's about 300 stores, each with about 70 people in each store. But having that decentralised approach to

HR, we rely very heavily on our training. In fact training becomes the mainstay of all people practices, and the line managers, so the restaurant managers, effectively become the people who hire, become the people who motivate, become the people who train, and we need to make sure that our training reflects society. So as a company we've become very training focused.

That's what my role has been. I've recently moved into the employee relations role. Before that, for the last five years, I was a training manager for McDonalds, and so I saw the policy implementation through training, but now I'm in a role which is a split role of employee relations and training. I get to do the other side, which is look at the policy review, look at the strategies that we're implementing, but also a large part of my role is to act as a person who can be called at any time, so I can get up to 50 or 60 calls a day from either parents, restaurant owners, employees, managers, and on a wide variety of aspects, so we have many different ways of trying to understand the employees but also employers, and that's really what my role is.

Why I wanted to talk today was to say that as a corporation I feel that I can now see that McDonalds has taken diversity on, as Rohan said, for two reasons. The main reason, as she said, is a business reason. But the thing I've realised is we don't have all the answers, and I'm finding now that the amount of committees and the amount of seminars that I can go to and find that there are other large companies that want to do the same and form networks is fantastic. We work with people like Diversity at Work and EMAD and Job Support, and we're looking to find as many pathways as possible.

It's good for me to know that McDonalds has a commitment at the top level to diversity, and in every mission statement that comes out or any policy that comes out, it's good that at the top level we have someone there on the HR that has a direct voice to the organisation, and in Victoria especially we're now working as a company. One thing I forgot to say was that the McDonalds company itself is 70 per cent licensees, franchisees, and 30 per cent company owned, and in a lot of the strategies that we implement, we try and make sure that as a company we have a focus and show the way.

At the moment we're working with Diversity at Work to enhance our training and also enhance some job opportunities, and we're working with them to look at all our company stores and make sure that we remove any barriers to employment for people with disabilities. We find the best way to give people with disability the best employment chances, so hopefully we can get to a stage where we can form a network, support groups, and make sure that it becomes a part of everyday business.

I'd say five years ago our training was mainly focused on what we as a company should be doing for people that are customers with disabilities, but it's been very pleasing to see over the last two or three years that we've been really working on employees with disabilities. Our training also moved from lecture style to facilitation style, and so the managers that come on the courses - there are four courses they have to come on before they become a restaurant manager - have now moved to facilitation style. So we're actually not just telling people what should be done; we're getting into groups and facilitating the right answers. So training is part of that platform. But, as I said, it's a long-term platform and we're working with as many other companies as possible because we're finding that we don't have the right answers all the time.

One of the things I've brought today is a video, just to try and demonstrate, and of course I know we don't have the time to show it, but it was taken from a 30-year anniversary, McDonalds had a one-hour show on Channel 7 and it was a documentary really of where McDonalds has started from and where it's come to. One highlight and one thing the company thought was very important to put in there was a story of a girl who works for McDonalds who has Down's syndrome, but catches the bus to work and has changed the management team - the team works as a team and it was a story just to show how important McDonalds takes diversity. I've got some things and maybe I should just leave them, which is really our training processes. It is just to show you what we're trying to do. We don't have all the answers, but we're trying to learn as much as possible.

MS McKENZIE: Thank you. You said, if I'm understanding you correctly, there has been a bit of a change in the way you've viewed your training over the last five years. You have changed from lecturing to facilitation and so on. Can you explain why? Why did that change happen?

MR WHITEHOUSE: I guess as you look at learning techniques and you look - I remember when I first went through my training it was one page full of writing and you took some of it in, you didn't take all of it in, and then people moved to PowerPoints and you saw people became PowerPoint hungry and you'd have 50,000 PowerPoints. Then, as you realised how much of that message was taken in and you realised it was quite a small amount, as a company we looked to see what was the best way of having the message stay, not just for that week of training but for the much longer term.

We found that by getting participation, instead of just telling someone, you would have a framework of where you wanted to go, but if you had that framework and let everyone else participate and come up with the answers themselves, it is something that they take on board themselves, and we've found the success ratio is much higher. So we're also finding that a lot of the ideas from my training are coming from the managers, because of their outside experiences. You know, you can set up a training package which has all the right things that you want to teach, but there are life experiences every day in our restaurants, so when people bring in those experiences, then the whole group can learn from it and not just from say, someone standing there doing a presentation, or a lecture. So that's why we've changed.

MRS OWENS: You also said that you changed the focus to not just look at customers with disabilities, but look at employees as well.

MR WHITEHOUSE: Definitely.

MRS OWENS: That was an interesting change.

MR WHITEHOUSE: I know that comes from a business sense, but when you look at your society and you look at how your society is changing and you start to work with your policies and also your training on how you should reflect that with the customers, then you realise that there are great employment opportunities as well, and so you look at the pool of talent out there and sometimes you want to make sure that you are attracting that whole pool of talent and not just certain pockets. So by changing the focus to employees as well, in a business sense you're going to attract more customers as well.

MS McKENZIE: Were any of the changes driven either by education which the Human Rights and Equal Opportunity Commission participated in, with the firm, or even perhaps complaints made under the Disability Discrimination Act? That's the focus, you know, of our inquiry, of course.

MR WHITEHOUSE: Yes. I wouldn't say it's been from complaints. I would say that as all businesses look at management techniques, they also look at the triple bottom line and all those sorts of things, and employer of choice - you look at what you need to do to become an employer of choice and you can have that as a slogan. You know, "We are an employer of choice," and those sorts of things, but until you look at the thing holistically and you look at what you need to do to attract people, and then when you're looking at how to attract people and you look at your image as an employer, that's when it becomes an integral part of your training. So it really wasn't - not necessarily from complaints.

MRS OWENS: Have you ever had any complaints?

MR WHITEHOUSE: Of or for?

MRS OWENS: Discrimination.

MR WHITEHOUSE: Not that I know of. As I say, I've only been in the role for about six months now.

MS SQUIRCHUK: One of the things is that McDonalds moved towards having a disability action plan in around - let me just get the timing right - probably 1999, the year 2000. I think part of that change was driven through the recognition of the way in which having a disability action plan actually focuses the organisation's mind at a more general level into some of the areas that you can do some work on.

MS McKENZIE: And that plan has now been lodged with HREOC.

MS SQUIRCHUK: I know they certainly worked with Graeme Innes on the development of that disability action plan.

MRS OWENS: Do you cover a wide range of disabilities in terms of the people that are employed by McDonalds? You talked about the young girl with Down's syndrome. What sort of disabilities do you also cover?

MR WHITEHOUSE: For customers and - again, just to start, most of our managers have come from crew. Even our CEO at the moment started as a 15-year-old crew person.

MS SQUIRCHUK: Hamburger flippers, they call them.

MR WHITEHOUSE: So you've got those - - -

MRS OWENS: Did you?

MR WHITEHOUSE: No, but I still had to do it. You still have to start as a trainee manager and work all the way through. The age groups that you've got - you've got to be careful with your training. As I said, it is a facilitation style and mainly it deals with either customers with special needs or employees with special needs. So you're not singling out any specific area, but in our training - which I'll leave here - for the managers that get to the stage where they're able to recruit people, we even in that situation have five different applicants that come, and they plan a role play situation. In that situation we have someone in the role play situation who has cerebral palsy. In our training for customers we deal with people who are hearing impaired, sight impaired. We talk about guide dogs. So we'll talk not so much on the legalities of why you should do it, but why it's best practice and why it's going to increase your customer base and why it's going to increase your employment base.

MRS OWENS: So do you have people with cerebral palsy, or people in wheelchairs working at McDonalds?

MR WHITEHOUSE: We've got people with various disabilities working at McDonalds. I couldn't say exactly who we've got where because we really haven't had a policy to sort of say, "We need a quota system of how many people in each restaurant." The training has been so that people see it as an employment practice, but we've definitely got people with many different disabilities in all restaurants - well, in most restaurants.

MRS OWENS: But you might need to measure something. If you've got an action plan, often actions plans have targets and so on, and you might at some stage want to say, "This is what our action plan said and this is where we've got to."

MR WHITEHOUSE: Definitely. As I said, we're working with a few organisations and we've got a charter that we're working on and the last section of that charter is to have an action plan and at the moment we're working with diversity at work and we are looking to employ a certain number of people. So, at that stage, we can say, "Have we been able to achieve this? What were some of the barriers? How can we move forward from this?" Then, once we've had a success there, that success can start to permeate throughout the whole organisation.

MS McKENZIE: Okay, so you are working towards that action plan?

MR WHITEHOUSE: Yes.

MS McKENZIE: At the moment with those sort of targets.

MRS OWENS: We might hand over to Cindy and you can run through what you were going to talk about.

MS BATCHELOR: Sure. I might just give you a little bit of background on the National, just to sort of position us. We are the largest financial institution by market capitalisation which is listed on the Australian stock exchange, so a very big employer. Within our financial services area we have 18,000 employees within Australia, but we also service three and a half million banking customers and over 2.2 million wealth management customers, so a significant proportion of the community are our clients. I suppose that's the focus of the business.

As Rohan mentioned before, in 1997 the National recognised the need to demonstrate leadership and best practice within financial services to provide equal access - I suppose this was from a customer perspective - to banking and financial services, products, premises and also to employment opportunities, although the employment of people with a disability has really become a focus in the last couple of years. I'll work through what our approach has been to that. So we did in 1997 develop a disability action plan which was the first to be lodged with the Human Rights and Equal Opportunity Commission under the Disability Discrimination Act, and we still have that disability action plan in place today, although it has taken on I suppose a bit of a different look and a different focus in terms of where we're going with our disability plan.

MS McKENZIE: So you've revised it along the way.

MR BATCHELOR: Absolutely - as we've gone, and we've learned as we've gone. It's certainly a journey for us. It's a long-term plan but it's something that we're committed to. We'll make some mistakes along the way but it's certainly part of the future for the National. Our disability employment program is actually an outcome of that disability action plan. We have targets and we have staff within the National who are accountable for meeting those targets. So I suppose we have put a stake in the ground in terms of what we want to achieve on those fronts.

The achievement of these programs - it's fine to have a disability action plan, but you need to monitor that and you need to monitor its progress. We have, I suppose, a disability employment program as part of a broader diversity program within the National, and we have a diversity guiding coalition, which has four focus areas: one being flexibility and balance, women in management, diversity of the top three layers of our organisation and indigenous and disability employment. Disability and indigenous employment are a key focus of our diversity program at the National.

The program's key aim is really to develop and implement long-term systemic as well as cultural change. It's not something that's going to happen overnight, and it has certainly been an education program. What we're aiming to do, though, is to maximise employment prospects for people with a disability. In the last 18 months our focus from an employment perspective has been on raising internal as well as external awareness, and also developing specialist, I suppose, relationships with specialist providers who are going to help us to meet those targets. We can't do it on our own. I suppose business is part of the equation, but the community, specialist service providers, government - we all need to be working together towards the same sorts of goals.

So we've been focused on really building those relationships. We've expanded our disability action plan to include employment specific strategies, whereas initially it was very much customer focused. We have detailed information, tool kits and training at the National specifically on disability. I've brought some examples of those, and they take different formats. I suppose we've recognised the need for our employees with disability to have different mediums, so we're fortunate - as a large organisation - we have a television network twice a week, which is a news service, and we can actually advertise and promote anything that we like, including raising awareness on that.

We have an intranet service which I suppose gets out to all our employees in remote locations and we have printed versions. I suppose we have looked at many different mediums so that we can provide access to the broadest range of employees. I mentioned before we have created partnerships with specialist service providers to ensure that all of our external vacancies are actually communicated to our specialist employment providers, so disability at work - employers making a difference. They have access to every external vacancy now. That is a manual process and part of, I suppose, our plan for improving our ability to create a diverse workforce is using technology, so having that be an automated process is something that we're working on now.

We've engaged specialist service providers for reasonable adjustment provisions and also to get work experience opportunities out there. We have diversity employment ambassadors within each of the business units, so that people with disability have a contact within their own business unit that they can go to and seek support, particularly if they don't really know how to go about getting that support. We've actually put some support programs in place.

As I said, there has been a very strong internal promotion, and we do have disability employment targets as a percentage of our overall recruitment target, so our managers are accountable for that - it's part of their key performance indicator - and they are rewarded on the basis of achievement of those objectives, so we're serious about it because we believe that diversifying our workforce and employing people with disability is good for business, but it's also going to add value not only to our employees, but to our customers as well, so it's really a win-win across the board.

MS McKENZIE: Can you give me some examples of your disability targets?

MS BATCHELOR: We look at what our external vacancies are and we set a percentage of that, so it may be 5 per cent of the total employment targets are going to be disability based. It's also connected with - we have a target as well for indigenous employment, so it becomes a percentage of the overall vacancies.

MS McKENZIE: So do you have a separate percentage for people with disabilities and a separate one for indigenous people that you - - -

MS BATCHELOR: Yes, we do.

MS McKENZIE: Okay.

MS BATCHELOR: I suppose we have gone along a path in the last 18 months, and it doesn't look like large number, but we've employed 31 people with a disability directly through this program. We have many more employees within the National who have disabilities, but they haven't been specifically recruited under this employment program, so we are tracking our progress against the program.

MRS OWENS: Can I ask what sort of disabilities you are employing?

MS BATCHELOR: I suppose it's a wide range. It's visually impaired, hearing impaired, physically impaired and also intellectually impaired, and we're able to make adjustments. As I said, we're relying on technology - hearing impairment, visual technology as well. Our call centres - you know, computers and technology are being - I suppose are purchased to ensure that they have the right facilities to be able to do their job, so it's right across the board.

MRS OWENS: Is anybody measuring the costs of doing this or is it just absorbed? It's such a big organisation.

MS BATCHELOR: Yes. No, we do, and we have within the diversity portfolio a specific employment area that looks after disability and indigenous employment, so, yes, they monitor that. They not only monitor the numbers of people, but also the cost because the business wants to know that, but we don't want it to be seen as a barrier to progress, so absolutely. At the end of the day I think we want to be able to measure how well we're doing. Now, that's in terms of numbers, but we also have to recognise that there is a cost, but we believe overall the benefits are going to outweigh that cost, no matter what it is at the end of the day.

MS McKENZIE: Is that the Victoria-wide program you're talking about - the 31 in the last 18 months - or is that Australia-wide?

MS BATCHELOR: That's Australia-wide.

MS McKENZIE: What kind of percentage does that represent of the people recruited overall in - - -

MS BATCHELOR: And we haven't hit the target yet - the target is the 5 per cent - but I suppose part of our approach at the moment is trying to raise awareness externally as well, and get the people through, so I suppose we're starting to create partnerships with people, so we can get the flow of people through the organisation, so even though we have the target and we monitor that on a quarterly basis, we haven't hit the target that we want to hit, although recruitment at the National isn't booming, so in terms of overall numbers it can be a percentage of no recruitment, but that doesn't stop us going through the process of actually getting people through the door and we have ongoing positions that people can apply for.

Also in the last 12 months 2000 people have gone through a detailed disability awareness training program and that's for people within the organisation who are working with people with a disability directly, so it's a team based approach, as well as providing - one of our disability action plan items is putting everybody at the National through generalist awareness training, and I've brought you a video which actually takes you through what that looks like.

MRS OWENS: Thank you.

MS BATCHELOR: Work experience and mentoring to disabled tertiary students: we are partnering with universities not only on the disability front but also on the indigenous front to try and get access again to young Australians who are interested in working for organisations such as ourselves, so again it is an awareness raising; offering signing courses within the National as well, for people who are working with staff members who have a hearing impairment, so we're actually going through that process - - -

MRS OWENS: Do many take that up?

MS BATCHELOR: We have actually gone through three groups of people, so those that are actually working directly with those who have the disability are taking that up.

MS McKENZIE: But could others - say someone in the south was interested - - -

MS BATCHELOR: Absolutely.

MS McKENZIE: Didn't directly work with someone with a hearing impairment, but knew of someone perhaps on another floor in their building - could they take up the course, too?

MS BATCHELOR: Absolutely, yes. It's offered I suppose as a generalist course, but it's targeted specifically as well in groups where there are people with those specific disabilities, so it's raising awareness of the specific group, but also allowing anybody who is interested. I suppose probably the training program at the National is that you can nominate for any course and be able to take that up, so, yes, it's offered to all staff, but it's specifically targeted at particular groups.

As I said before, technology is playing an important part in our ability to provide the right working environment. As I said, we've made adjustments or purchased software in call centres for people with a visual impairment. The whole of the training program is being visually captioned, so that we have a captioned format throughout all of the new training that's coming on board and we're going back through the old training as well, so that we're making adjustments to that.

As I said before, it's been a journey and we've got a long way to go and, having focused on employment just in the last 18 months, we're starting to look at what targets we want to try and achieve, but it's also, in a workforce our size, pushing that down the line. You know, it's getting that down to line manager level, because they're the ones that are going to be doing the recruitment, and they're also the ones that are going to be working with the people, so it's an education process and it's not a quick one, but we're trying to use as many mediums as possible to get the message out there that, as an organisation, we're serious about trying to diversify our workforce.

MS McKENZIE: I'm going to ask you a similar question to the one I asked earlier. You've already talked about your action plan. Do you see these processes as one of the outcomes from your action plan or has it been at all driven by any complaints that might have been made under the DDA?

MS BATCHELOR: I couldn't say we haven't had any complaints, but it has been driven more by, I suppose, the recognition of a need to do something and to create an inclusive workforce, and also to be more reflective of our customer base - I suppose a recognition that our employees are pretty reflective of the community, or should be, and we need to diversify our workforce, whether it be through disabled employees or whatever, to be more reflective of that, so that's probably the driver, and also because we believe it makes good business sense to do it and, being a bank, that's a fairly strong driver. They're not so much as a result of complaints, although I think you need to recognise that you have to deal with that and that's going to be part of the process and we're not going to get it right every time, but we have got a plan in place to try and improve and to progress - I suppose a very important plan for us going forward.

MS SQUIRCHUK: Can I maybe make some closing comments - - -

MS McKENZIE: Sure.

MS SQUIRCHUK: - - - just to say that in ensuring that we came not just from the Cuncil for Equal Opportunity, but in bringing partners along from our large businesses, it was around saying the Disability Discrimination Act has made a difference. These organisations have been in it for the long haul in terms of disability action plans and looking at the way in which they can move forward, and part of the role of the act obviously is awareness and education raising. There are many examples - these are probably two of the better ones - that could be profiled to demonstrate models of success.

They're not about getting it right 100 per cent of the time - and we've talked about that - but it's very much about maximising the opportunities available at all levels from a community point of view, a business point of view and a government point of view in a partnership to make the way in which employment works and opportunities within Australia are available to all of its people, and that's part of what we - the council and its members - set. We've worked closely with the government in the past. We see there is a strong need for practical assistance for employers, which we've talked about partnering with a number of specialist agencies, but the leadership role of the government and HREOC, the Disability Discrimination Act and that part of the Human Rights Commission is a very important part of making sure that employers are aware of their responsibilities.

MRS OWENS: I think we could probably talk to you all day because there's a whole range of other issues - we've just talked to very large employers, but I suppose there is the issue of how smaller members are coping with all of this. It becomes more difficult if you've got 15 employees or less, or fewer - - -

MS SQUIRCHUK: I know from the council's personal experience that the reality around it is that we recognise that if we aren't a person with a disability ourselves, that we're an associate or a carer of a person with a disability, and we all have to pull together. As the business manager of the council, some of the experiences I have had have been extremely challenging but they're experiences I would never have missed. They are like being a mother in a way. It's part of the rich tapestry we have.

MS McKENZIE: We could ask lots more and talk for lots more, but - - -

MRS OWENS: There's the whole question of affirmative action that some people have raised as another approach.

MS SQUIRCHUK: I actually would like to talk a little bit about that. At the council when the commission's terms of reference were first announced we were really trying to engage our members to put submissions and to come forward, et cetera, and one of the things is that business is so competitive - the amount of time people have to do that is just less and less available - and, as I said, I think that the challenge in terms of doing more with less the whole time is really pressing many businesses, but I think one of the real challenges in terms of affirmative action and a program like the Equal Opportunity for Women Program, as an example, is that it's pretty easy most of the time to determine whether your staff are female or male. It's generally not so easy as far as disability is concerned and often people don't want to disclose they have a disability, certainly at the beginning, because there is a fear of discrimination if you disclose.

I think that is probably the strongest thing I have seen in terms of mental illness in my time with the Mental Health Review Tribunal: first of all, there is this enormous fear - because I think there is an underlying thing of, "There, but for the grace of God" or, "It's just around the corner for me in terms of mental illness" - because one in five of us will have a period of mental illness during our lifetime, but I think that, knowing what to do - and probably from our small employers that's really where the inquiries come. I have got someone who is displaying hypervigilance or symptoms of paranoia, as an example, and I don't know what to do. Assisting them through that process, finding access to services is part of the work that we do. But more and more, in order for us to have people available to work, we are going to have to accommodate all areas of difference. That challenge is one that some of us welcome and some of us want to walk away from.

MRS OWENS: Thank you very much for that.

MS SQUIRCHUK: Thank you all very much.

MRS OWENS: If you ever find any really terrific examples of small employers who are implementing action plans and so on, we'd be very grateful for that.

MS SQUIRCHUK: Yes, I'll ask around.

MRS OWENS: Okay. We'll now break and we'll resume at 20 to 2.

(Luncheon adjournment)

MRS OWENS: We will now resume. The next participant this afternoon is the Australian DeafBlind Council, ADBC. Could you please give your name and your position with the council for the transcript.

MS TRENTINI: Yes, it's Meryle Trentini, and I am the treasurer of the Australian DeafBlind Council. I also work as the community and day services manager at the DeafBlind Association here in Melbourne.

MRS OWENS: Good, thank you. We received the other day some points that relate to what you'd like to raise with us today. Maybe I'll hand over to you and we can go through each of the points. You were going to give us a description of the background on the ADBC and the deafblind community and then raise some issues related to the DDA and the impact on specific activities. Maybe we will just go through each of those in whichever order you wish. But maybe give us some background first, which could be useful.

MS TRENTINI: All right. The Australian DeafBlind Council is known as the national level special interest group for deafblindness. It's a voluntary committee. It's not funded officially from any government body. It comprises seven members; three people with deafblindness, one parent and three service providers, and representatives come from New South Wales, Western Australia, Queensland and Victoria. Do you want me to move on?

MRS OWENS: Yes.

MS McKENZIE: We will sort of - - -

MS TRENTINI: Interrupt.

MS McKENZIE: Ask you questions - yes, we'll interrupt you.

MRS OWENS: You got going in 93 or something, is that right?

MS TRENTINI: Yes, it's about 10 years or so. I thought, to help put the comments I'm going to make in context - because obviously reviewing the whole act is a huge task, so I've tried to narrow down to just a few things. But it is important to talk a little about the deafblind community. This community consists of people with differing combinations of vision and hearing loss, either acquired through accident, illness or genetic reasons such as Usher or other syndromes. Communication and mobility issues are central. The concept of being deafblind is frightening and generally people do not want to think about it. I don't think anybody here would be any exception to that.

The National Deafblind Forum was held in July 2001 in Sydney and I’ve drawn a few comments from the report that was made by Mike Steer in relation to that forum. Mike is also a committee member. They made it clear at the forum that there is no state or territory which comes close to meeting the needs of its citizens who are deafblind in any of the areas of the CSTDA or in education, transport and health. Australians who are deafblind have traditionally been in the too-hard basket or in the "fall between the cracks" category.

They reported the following issues: that there is no coherent national or state policy or planning regarding services for people who are deafblind. There is no policy level recognition that deafblindness is more than the sum of its parts, requiring additional focus and support; no funded individual group or systemic advocacy services in any state or territory focusing on the needs of people who are deafblind; a lack of appropriate training in the area of deafblindness to ensure quality staff and services; lack of consistency between states in the ways they provide services; no recognition of the communication needs of people who are deafblind; or their right to participate in their communities; no recognition of the increasing incidence of deafblindness and its associated issues as the population ages, and no research into specific areas of deafblindness, including needs of service providers, interpreters, families and advocates.

Historically deafblindness has not been recognised as a discrete disability and, as it is a low incidence disability, by its very nature, it can remain isolated and hidden. It was estimated in research undertaken in the early 90s that there are approximately 1500 people with deafblindness in Australia, but again that’s an estimation and there is no additional research at this point. The first language of many people with deafblindness is auslan, Australian Sign Language, which in itself was only recognised as a language in the late 80s.

Methods of communication in the community are varied and include different forms of signing, including in-the-hand finger spelling, tactile sign, note taking. The notion of a deafblind community has only been developing over the past 10 years or so. With struggles to gain services as a priority the community has been lagging behind in its opportunity to make use of the DDA, and I think that’s a really important point. In essence the DDA is older than the community, and the community is just catching up in its understanding of the act and its implications; the act which is now under review.

It’s not surprising that, with some concern, I note this inquiry has stemmed from the Commonwealth government’s commitment to review legislation that might restrict competition. I think the economic imperatives are certainly ones that would not be seen as the high priority from our point of view.

If I can just touch briefly on some of the specific activities that come under the act - employment: some years ago in Victoria a sensory-specific employment organisation was established with Commonwealth funding. Appropriate adaptive technology was provided and sensory consultations with appropriate skills in communication sighted guiding, et cetera, worked with potential employers and employees to support mutually beneficial work outcomes. A change in government policy effectively removed the necessary resources and support. Is this discrimination?

A high proportion of the deafblind community would be amongst the chronically unemployed; not unemployable - unemployed. No change to eligibility for the disability support pension will increase their opportunity for employment. Without appropriate resources and support their isolation remains. Education: obviously with auslan, a visual language being the primary communication means, English literacy is an ongoing issue. In relation to education, some years ago a deafblind person enrolled at university with interpreting and guiding support provided through the disability liaison unit. After a few weeks of struggling to cope with the pace and demands the deafblind person stopped attending. He then received, and continues to receive HECS bills from the Tax Office. He was not informed at enrolment of the strict requirements with regard to withdrawing from classes. He was not able to access all the information available to other students and the bureaucratic requirements were not met. Is this discrimination?

Advocacy: without resources deafblind people are disempowered and currently there are no resources to support this activity.

MS McKENZIE: Sorry, are you going to talk about education specifically later? You've talked about employment specifically, so do the same problems apply in education?

MS TRENTINI: I think you could safely say the same problems apply across the spectrum.

MS McKENZIE: Yes.

MS TRENTINI: Information: accessible formats are essential and customised according to people's vision. There has been quite a development in terms of accessibility, but certainly not right across the range of things as yet. I note that the Productivity Commission's publications are available in large print and I saw a Braille copy out on the table. I hope it also includes plain English and COMPIC. I'm not sure, Helen, that's perhaps a question I could ask the - - -

MRS OWENS: We did a plain English set of questions at the outset, but most of our publications and reports tend to be fairly complex documents and it raises the question of: who is the audience? At particular times the audience is going to differ, but what we're going to try and do for this particular inquiry is to make sure that the report we write is as simple as possible; maybe there will be a stand-alone plain English overview, but at some stage we need to develop a report that will go to government and be read by people in different departments, and form the basis of policy decision-making, so we need a report that's going to focus on that, at that stage, but we also - in the meantime when we do our draft report - need to be able to get out some of our key findings and recommendations in a very accessible way. The challenge that we face is how we are going to do that. We are still working through that.

MS McKENZIE: Can I ask you what COMPIC is?

MS TRENTINI: It's illustrations which mirror the concepts that are being presented in the text.

MS McKENZIE: All right.

MS TRENTINI: In relation to accessibility it is essential to provide people with the opportunity to grasp the concepts of legislation and standards in order to participate in their development or review. The information technology revolution has also transformed the lives of many people with deafblindness. The ADBC actually meets via email. This has been a major change, which is wonderful. Here in Melbourne we actually have what is called The Link - a computer and Internet access training centre for deafblind people - and it was established with Commonwealth government funding through the accessibility program under the Department of Communication, Information, Technology and the Arts. This centre trains both local and interstate participants but, as with employment, a change of government policy saw the end of funding and its very existence is now dependent on trusts. Is this discrimination? Submissions to the Victorian government to connected communities were unsuccessful because the target group is too small. Again I ask: is this discrimination?

Moving way from activities - because every area that you looked at, whether it be transport or service provision or whatever, you would find similar themes running through in relation to this particular community. Just some of the issues that I'd like to briefly talk about: with regard to the DDA we've already touched on language, but to reinforce, with language auslan is visual; it's not a conceptual language and terms like "bodily integrity" are seen as a potential issue with regard to equality before the law and the DDA are meaningless when translated into auslan. Again, I think this acts as a kind of a double discrimination with the language acting as an additional barrier.

The concept of unjustifiable hardship seems ironic that this applies to employers. Surely the people experiencing this are those with the disability. Using language with such negative connotations surely reinforces barriers to participation. Perhaps new terminology is required. Maybe "justified exemptions" or something similar, but I think the concept that the actual wording needs to be considered. Measures which promote more proactive participation by employers, such as tax incentives or the five-tick quality accreditation for employing and appropriately supporting a certain percentage of people with disabilities and equipment subsidies, should be integral and monitored, if we're serious.

Reasonable adjustments in the area of deafblindness can be costly. For example, a refreshable Braille display to access the computer can cost approximately $11,000. To take this seriously requires positive discrimination and government support. We would be concerned that any changes are going to make this even less likely for people to be supported with employment.

From our perspective, the existence of the DDA has been influential. Just having an act has been significant in itself. It has contributed to community awareness. However, disability is not - and I put this in inverted commas - "a sexy area" when it comes to allocating resources, and I think this is a major challenge. We don't have the resources to support people to pursue action under the DDA.

The deafblind community has only been able to participate to a very limited extent in the process. The language, the complaints process, the degree of support - a lot of things make barriers to actually participating. Living with deafblindness brings demands that we can't imagine. A couple of those, which are constants, is the amount of time that people can concentrate, receiving their information and communication via a different means, and the tiredness because of that.

I think the processes need to be much more streamlined, and obviously need more resources. We would still support, at this stage, legislation that was disability-specific. From the deafblind perspective, we're not far enough down the road yet; the system is not yet sufficiently equitable. We need to put energy into making the act stronger, and if the other aim is to increase competition, I guess the question is: is that incompatible. Thank you.

MRS OWENS: Good. Thank you very much. You've raised a number of issues. One you just raised towards the end was this issue about deafblind people not being able to really avail themselves of opportunities under the act. For example - I think you talked about making complaints, or even just understanding the educational information that comes out from HREOC.

We're hearing that in other areas as well, like people with intellectual disabilities also may face similar problems - they're not the same, but they're similar problems - and other people in institutions that may not be able to get access to information at all, who also may have an intellectual disability. This isn't a question. It's really just saying that you are raising some issues that we're starting to hear - - -

MS TRENTINI: Across the board, yes.

MS McKENZIE: What ways do you think might be adopted to address some of this? I mean, for example, I can see there needs to be obviously a good deal more consideration given to information in accessible formats, and maybe there needs to be - you have said that you meet by email, haven't you?

MS TRENTINI: Yes.

MS McKENZIE: But that's your committee.

MS TRENTINI: That's the committee. That has on it, though, three people who are deafblind.

MS McKENZIE: Yes.

MS TRENTINI: And for people who have the literacy skills or the opportunity to have further training, the email is wonderful for all sorts of reasons, yes. Certainly they would access, like, the web sites. But again, the language could still be a potential barrier, unless things are coming out in plain English, because it's a second language for them.

MRS OWENS: Do you think HREOC or others need to be able to make a special effort, beyond language, like more information for these particular people? Are there special issues that may arise for them, that don't arise for other people with disabilities, that HREOC should be acknowledging.

MS TRENTINI: Well, I think, in terms of face-to-face contact, then yes, there are, because you have - I'm not sure you're well aware - the issue of interpreting services and having access to interpreters, and the costs associated with that. Another issue, of course, is the fact that they - in order to advocate for themselves, because I mean, today it should actually be somebody with deafblindness here, and not myself.

But there is no - deafblindness covers a whole range of different combinations of vision and hearing, so it's difficult for one person to represent the range of deafblindness. Also there is nothing at this stage - unlike some other disability organisations that have very strong self-advocacy, as yet deafblindness doesn't. So we're still behind in regard to those sorts of things, where people can come and present. But if they did, you would have the issue of them coming with appropriate support, and that's costly. A minimum interpreter booking costs $108, because you have a minimum two-hour booking. So to bring an interpreter with you is a very expensive exercise.

MRS OWENS: So thinking about the HREOC process, where they may want to put in a complaint and then go through a hearing process, what you're saying is that there are considerable costs associated with that.

MS TRENTINI: Yes.

MRS OWENS: Plus they may want to take an advocate, and you said earlier that there's no government-funded advocacy groups as there are for other groups in the community.

MS TRENTINI: No, and they would not be able to access the hearing without sighted guide support - have an additional support person, as well as your interpreters.

MRS OWENS: I presume within this group there's going to be some people who are not going to be able to use an auslan interpreter either - - -

MS TRENTINI: That's right.

MRS OWENS: - - - if they're sight is - well, if they were like Cate, for example, that would be a problem for those people.

MS TRENTINI: Well, no. In fact, they do use what's called tactile sign, so it's hand-on-hand signing. A lot of them who are fluent in auslan would use tactile sign, but people who have perhaps lost hearing later in life and are not familiar with auslan, then yes, you would require note taking or some other form of communication method with them that enabled them to participate in the process.

MS McKENZIE: And extra time would have to be allowed for that process. That's the other thing.

MS TRENTINI: Absolutely. Yes. Extra time, and then you couldn't have, like, a continuous - you couldn't do a day, because the demands would be too great. So, yes, there's all those sort of complexities to do with actually people being able to participate.

MRS OWENS: Presumably with interpreters, some of them are going to be quite specialised and others might be able to do the tactile work, and you've got to get access to those people as well.

MS TRENTINI: That's right.

MRS OWENS: And possibly you'd have to wait for those people to be available. Is that right?

MS TRENTINI: Not all auslan interpreters are skilled or keen to work with deafblind, because their skill is with auslan, which is working with the deaf community. But there are a group who are experienced in working with deafblind, and adapt and accommodate to the needs of the deafblind people, and they're the ones that you need, yes.

MRS OWENS: Are there many of them?

MS TRENTINI: No. All these things vary across Australia. I mean, the most development of services has occurred here in Victoria, but the Australian scene is really - in some parts, is really quite dismal.

MS McKENZIE: But because of these difficulties, would it be helpful - I'm not saying as a substitute, but as an alternative method, if you like - if the commission or perhaps a representative organisation, or an advocacy organisation, could actually complain - perhaps even, not necessarily exactly on behalf of a deafblind person, but on information which they've received?

MS TRENTINI: I think that's true, Cate. I guess at the moment, as I said, with the community, the struggle is to get services. When people have services, then I think they're then more able and more energised to put their energies into something else, and it does require that, doesn't it, to take things to the next level.

MRS OWENS: Do you think the issue of service provision is something that should be tackled through something called a Disability Discrimination Act, or is it something that needs to be tackled in some other way?

MS TRENTINI: This is perhaps a personal view, not necessarily the council's view, but I think in so many areas we are still so far behind that anything that can be developed that actually protects and promotes the rights of people with disabilities, that's what we should be doing. We haven't yet reached the luxury of the point of being able to say, well, we've got enough. We're still really just - I mean, this community is behind other communities in relation to that.

MRS OWENS: One of the challenges that we face is this issue about adequacy of services and distribution of services and so on, and it's a question of how much that issue can be addressed through this act, and how much of it is a broader issue, about government's responsibility to supply services - you know, service provision that comes in under other acts, administrative arrangements, and so on. There is a Disability Services Act as well.

But what we're going to be doing is, where we have got these broader issues, we will be bringing those to the government's attention and saying, "By the way, this is what we're saying about the Disability Discrimination Act." Some of these issues will be relevant. To the extent that they fall outside our terms of reference, we'll address them anyway. But what we are saying is that if people don't get access to certain services, it may then jeopardise their ability to be treated equally in the community.

MS TRENTINI: That's right. Absolutely.

MRS OWENS: So we're recognising that, but it's a matter of how much you can deal with that within the narrow confines of this act. Maybe the act could be strengthened to make that a more direct part of the act, or maybe it needs to be thought about in another way.

MS McKENZIE: Some of it might be a question of indirect discrimination as well, particularly if you're really saying to a deafblind person, "Look, if you want to do this particular thing, you've got to do so with whatever's available in the community, but not with any extras," and that's a possible indirect discrimination case, because you're saying that the person who is not deafblind can easily - with whatever is currently in place - access whatever service it is, but the deafblind person cannot, without extras.

MS TRENTINI: I'd agree with that, yes.

MRS OWENS: Can you give us some feel for what happens in education? How many of the children that are deafblind are integrated into the mainstream schooling system? Are very many?

MS TRENTINI: That's a difficult question to answer, and I think it probably varies from state to state. I think there has been some specialised education in states rather than necessarily integration and again coming back to the communication needs, so it's not necessarily going into the general mainstream schools.

MS McKENZIE: So this is in special schools rather than in special units.

MS TRENTINI: Even in units that are targeting very much people who have the combined sensory impairment and not necessarily other disabilities, but sometimes it's combined with other disabilities. There's not really a straight answer. Quite a few people that we would provide services to in Victoria have come through the deaf school system and others have had early childhood development through the blind school, so it's kind of a combined situation.

MS McKENZIE: But very few, you would say, have tried to enter into the general schooling system and get support through that system?

MS TRENTINI: Yes, because the issue of communication comes up all the time.

MS McKENZIE: Under the DDA currently there is a transport standard. There is perhaps going to be an education centre, although it's still not quite clear where that's all leading, but do you have any comment to make about what effect those standards might have to improve the situation as far as deafblind - people with disabilities are concerned?

MS TRENTINI: I know that there has been some participation in the committees that have been looking at the development of those standards and - correct me if I am wrong here - I know that there was some dismay when - I think the tramways here were given the temporary exemption that was going to last about 20 years or something to make gradual modifications to the transport. It's at the point now where there is - and I am speaking in Victoria now - an increased awareness that there is this group in the community and they are able to participate more in the consultations around those things, but it doesn't mean that the decisions or what's actually being developed isn't already so well advanced that any recommendations they might make are - it's kind of after the event.

I'm thinking here about the changes made to Flinders Street and the height of television monitors, the colour contrast that was used in the size of the print. The fact that there are announcements for people who can hear but, if you are deaf, there is no sort of other warning thing, so a lot of issues like that that have not been incorporated. I mean, public transport, yes, still remains a huge issue, and I guess like anything, standards help; like it's beginning part of the process that you actually have something which people have to work towards, but I think sometimes it is a bit after the event, so you have got to wait for the next developments to have the changes.

MRS OWENS: I suppose the next opportunity you get is the redevelopment of Spencer Street station.

MS TRENTINI: Yes.

MRS OWENS: And that's one where it is a total rebuild, so maybe that will mean that there will be more flexibility and maybe more responsiveness, but with the sorts of issues you raised about Flinders Street it is a matter of feeding that information back to the planners, so that they are aware - - -

MS TRENTINI: That's right. As I say, when a set of new trains came people were invited to go and try it out and give their comments and so, in a sense, they're part of that. There has been recent involvement with the rail crossings, so certainly we are attempting to have input into all those things as they come up, but again it's like that next level when people are still needing services to do their normal daily things or go to a doctor's appointment or something, then to put energies into those things - it's another level altogether.

MRS OWENS: Yes. I just have one other issue and that's the issue about the coverage of the act in terms of the deafblind, and whether you think that there has been too much emphasis through the legislation on specific disabilities rather than people with multiple disabilities, or do you think the act has been neutral in that regard?

MS TRENTINI: I probably wouldn't be able to comment on that, Helen. There would be other people better able to comment on that.

MRS OWENS: Okay. Thank you.

MS McKENZIE: That's a very helpful submission for us. Thank you very much.

MRS OWENS: Thank you for that. Was there something else you wanted to say to us?

MS TRENTINI: No, I don't think so.

MRS OWENS: Thank you.

MS McKENZIE: That's really good. Thank you very much.

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

MS McKENZIE: Our next participant is Niu Ze Qun.

MS NIU: You are absolute right.

MS McKENZIE: What I would ask you to do is to give your name for the transcript, and also the capacity in which you are appearing. Do you then want to raise some key points about the presentation you are giving and then we might, along the way, ask you some questions.

MS NIU: Yes, okay.

MS McKENZIE: We're Helen and Cate. We're calling you by your given name, so - - -

MS NIU: My surname is Niu. Christian name is Ze Qun. The main things I want to talk about is about the people who come here and English is not their first language and where they have the physical problem - like injury from work - how do they get help? How do they get any support? From my experience that's what I find out - lots of people like me don't know where to go to ask for help. That's the main thing.

MS McKENZIE: You didn't know who to go to get the information about what you should do when your injury happened?

MS NIU: No. Even someone told me, say where I get injury - because overwork on the computer. No-one told me - said should have 15 minutes no work on computer; need a break. No-one told me. So I work two hours, three hours. Yes, we did have a break; like I have lunch; finish 12.30, and I start work from 1 o'clock in afternoon, so afternoon time is 3.30, so between 1 o'clock to 3.30 no break; on computer all the time, so I got injury, and before get injury no-one told me should have a break for 10 - to do some stretch; do something else.

So after I get injury I did mention to my supervisor. I said, "I got a sore back." So she said, "Everyone have sore back," so I said, "Everyone have a sore back, so why I'm so fussy or something about my back?" and after that I didn't get a treatment properly. I don't know whether I have what is call RSI. Now, years later, I remember the name. At the beginning they said, "RSI". I said, "What is RSI? Don't know." Only getting to know afterwards, so I think if we know something before the accident happen or some injury happen, I think I can avoid. The things is better for all the people, all the parts involved.

MS McKENZIE: And then eventually you got worse. You had to quit work.

MS NIU: Yes, and after the doctor say that - after I feel the muscle with pain I went to see doctor and the doctor said, "Oh, yeah, you have some problem, but it's not severe," so I said, "It's okay," so I keep going, going, work full-time for 18 months, without the proper treatment, so at the end - and my neck - you know my head and my neck are really separate; like my neck didn't listen to me, and sitting there, watch the television, can't stand up, and lie on the bed - I cannot turn left, I cannot turn right, and when I talking to you at that time in 95, my neck is stuck and I have to pull my head, slowly go back, I still working, and no-one said it to me, "Go to see physiotherapist." I don't know what even physiotherapist at that time. For 18 months so the treatment be delayed. So later on went to see doctor; want physiotherapist. He said, "Why didn't you come here to see me earlier?" I said, "I don't know." That's all. Lots of things I did answer, "I don't know."

MS McKENZIE: After all the injury and then after you had to finish work no-one told you about - - -

MS NIU: No.

MS McKENZIE: - - - discrimination complaint or - - -

MS NIU: Yes, and you see when on that stage I was in - really I said, "I don't know where to see the doctor." I just went - there is a clinic in the university. I work for the university - clinic in - so I said, "Save the time, going travelling somewhere to see a doctor." There's no problem; come back for the carpark; once you drive away, you come back, there's no carpark, so I stick with the doctor in the university and he said, "You're okay, but I not really bad. You're okay. Still can do it," so it's not severe, so that's the answer, the reply I get it from doctor, really.

MS McKENZIE: Sorry. Can I just clarify. You filled out a WorkCover form - - -

MS NIU: Yes.

MS McKENZIE: - - - but you didn't take - - -

MS NIU: Didn't take a day off, no.

MS McKENZIE: - - - any time off.

MS NIU: No.

MS McKENZIE: So you never got really into the workers compensation system - - -

MS NIU: No.

MS McKENZIE: - - - so you didn't have rehabilitation for the RSI - for the condition?

MS NIU: No.

MS McKENZIE: And no-one explained - - -

MS NIU: In 18 months I didn't have any. After 18 months, when I hanging on the clothes, so the head like this - I have kneel down to pick another - the head can't move until there, so my friend said, "Oh, oh, you should going to the doctor somewhere else. Don't stick with this doctor," because I stick with this doctor for 18 months, so she said - she took me to going to see her doctor outside, so like I fill the form "unfit to work", so start take the - have rest after that. After that I still go back to work four days a week, two days a week. Try to still work but I getting worse and at night can't go to sleep and had a nightmare always, and take the tablets for sleeping, and sometimes really embarrass when going to work - get in the library - I work in the library - urgent want to go to toilet; rushed; can't; getting wet; go home to change. So all those things happen, and the heart - irregular beats. I went to lawyer, Melbourne hospital to do the ECG and the - stop beating a bit all time before, at the beginning, a few times a day, later on - 24 hours, all time - jump, jump, stop, jump, jump, stop. So all these things happen, so end up my friend said, "Don't go to work any more because you are getting worse" - lots of things were happen, so later I stop. All the treatment, the rest, happen after 18 months.

MS McKENZIE: And no-one told you that you could go to complain to anyone?

MS NIU: Where? No. Later on I went to see the union person in the university and because this one only branch, they say this one is a very difficult. They refer me to the - what is it? The national tertiary - what is Australia union. Went to there. It's a lady. She took me - she said, "I need going to the lawyer," so later on we went to conciliation with a lady from the union together, but still I did not have the information which I should, for example, and I went to see a doctor; get unfitted to work certificate once a month, so for 12 months - after that I receive letter from the university, said, "Because you are ill - haven't got good health - so you be term - - -"

MS McKENZIE: Terminated.

MS NIU: "Terminated", yes. They ask me sign on the letter, so I ring the lady in the union and both of us went to see the lawyer. The lawyer said, "What can we do? Just sign on it." Sign on it? That's all? Sign on form. But after that - and someone said it to me - I should - what is it? - going to common law, or something. What is the law, and that they have limited time for six years or five years, otherwise will be lost - my right will be lost; can't going to sue them or something for the limit of six years. I don't know what - when they talking about this one I said, "My injury happen in 95, so by the 2000 and something it's already after the six years," but the solicitor and the union person - none of them mention it to me. Say that in 12 months I will be - kick it out, you know, from the university. I don't know. I don't know these things - what is the law over there.

MS McKENZIE: So it would be much better if you had got the information early, not late - not so late - and a lot more information?

MS NIU: Yes. I don't know all these things. I don't know all the things.

MS McKENZIE: Mm.

MS NIU: Because I love my job. I work 10 years in the library when I was in China. After come here I was really out of a dream. I got same job - exactly the same job - in the library. I was so happy. I told the college - I said, "I will work here in my life." I never think I got it now - because physical problem - kick it up.

MRS OWENS: So are you working now?

MS NIU: No, and what's happen now - I still, still, apply lots of different kind of job, but I need a referee, so I ring to my supervisor in the library. She said no, she doesn't want to be my referee, so special lots of places want the referee from your workplace, so I can't find anyone to be my referee, so I couldn't find a job. I apply in last two or three years. I apply lots and lots of different job. Try to do something as a part-time. I say I can't do the full-time. I can do the part-time, but no, no referee. Can't find any.

MRS OWENS: Have you managed at any stage to get as far as an interview?

MS NIU: Yes.

MRS OWENS: And have people asked you about whether you had time off or had a workers compensation claim or about whether you have been sick? Have people asked you that while they were doing the interview?

MS NIU: No. They said, "Why did you leave the previous job?' so I said, "I overwork on a computer and got RSI," so they said, "Okay." They didn't say anything. At the end I got a letter, "Unfortunately" you know, "you are" something, so - and another thing they say - even not really for looking for the job. Even I looking for the partner, because I'm single, try and find someone. They always said, "You working at the library. Why do you not work there any more?" I said, "I got a sore back because I overwork on the computer," and they never come back. All those things.

MS McKENZIE: That's very difficult. That puts you in a very difficult situation.

MS NIU: Yes. So if someone said it to me, said, "Be careful. You only have 12 months limited leave the work under the sick" - under the unfit certificate, and if after 12 months you were kick it up, if someone warning me, maybe I you know go back to work for a while, or maybe work over there for part-time, looking for something else in the university. Instead, I don't know anything and 12 months, knock out.

MRS OWENS: The university within that 12 months made no effort to find you another job or to adjust your workplace to make it easier for you to work in that job?

MS NIU: Yes, and I did ask the university - and the lady from the union, we did ask them. No answer. Never got answer.

MRS OWENS: They never replied?

MS NIU: No answer. Even I been knocked out, before I knocked out, before I receive a letter say that terminated, didn't hear anything from them, not anything. No words. When I went to some conciliation or something should be five different part, you know - me, the lawyer, my lawyer, and the lady from the union, and from insurance company, from the conciliation, but none of people from the university - none of them.

MS McKENZIE: So the university didn't come to the conciliation?

MS NIU: No, no.

MS McKENZIE: That's very hard to understand because the university was your employer.

MS NIU: So maybe they ask the insurance company instead for them - ask the insurance for them.

MS McKENZIE: Maybe.

MRS OWENS: The insurance company was probably representing them.

MS NIU: For them, yes.

MS McKENZIE: Even so, quite often the employer will come as well. It's very surprising.

MS NIU: No. After I receive the letter for terminating or something, I sign, and the lady from the union - she was really supporting me. I said, "I don't know the language - how to say properly - and I even don't know how to make a question to ask. I don't know what is my rights," and so she always coming with me. She point out a lot of questions.

MS McKENZIE: So she was very helpful?

MS NIU: I think so. Without her help I still sitting there, you know - even to move anywhere. You don't know where to see the lawyer. The one thing I still feel unhappy - even she didn't tell me - I don't know she know it or not - in 12 months it's better if I can do something, go back, I still keep my job. She didn't mention to me and my lawyer didn't mention to me. I don't know.

MRS OWENS: The difference is that if you had gone out on workers compensation and had time off under workers compensation then they would have had to have given you a rehabilitation provider and they would have then had responsibilities to try and adapt the workplace and provide a means by which you could get back to work, so that your injury was not aggravated, so there would have been a number of measures that the university would have been required to carry out, but because you didn't get past filling in the form and didn't know that that's what you could have done you ended up in this other system - or lack of a system.

MS NIU: When I got this letter I even check the word - What is "termination"" - you said it. Say, "Go out. You finish."

MRS OWENS: Yes, it means finish.

MS NIU: I check the dictionary. What is this?

MRS OWENS: It won't surprise you to know that we have had other people from non-English-speaking backgrounds also talking to us about their problems in various contexts and the difficulties they have in terms of the act we're looking at. A lot of people say, "Well, we didn't know it was there. We didn't know what our rights were under that act. Even if we did, it would be very hard for us to put in a complaint, because we don't have enough English." So we're getting quite an interesting story.

MS McKENZIE: They also say that even if you get the information - you know, you can get a brochure or a piece of paper with the information - it's not in very simple English, it's quite hard to understand; just like the termination letter.

MS NIU: When I got the letter, they asked me to fill it in because it helps or something. I said, "What is this word?" Find out from dictionary.

MRS OWENS: You possibly could have said, "I'm not going to sign this until I get somebody to explain what it is that this letter is doing," but you don't know that.

MS NIU: No. So I think that really what is a better way for all of the employees, they should get some information before they make the big decision. This is a big decision for me really, in my life, and I didn't get any one word from them. Those are things are feel are - - -

MS McKENZIE: You feel it's unfair.

MS NIU: And I think of how many people like me, you know, in this - have this kind of problem.

MS McKENZIE: Yes, from many different countries.

MS NIU: I think lots of people maybe from different companies or different workplaces, they should get some more warning - if we don't come in on such and such a day, something will happen, so I can make a decision, I go back to work for a time, or still stay at home, don't go back. I don't know - either 12 months, depends.

MRS OWENS: That time you were home over that period, were you on sick leave?

MS NIU: No. You see, the sick leave - I used my sick leave after I received this letter - termination, because the lady from the union said it to me, "How many sick leave do you have?" I said, "I have about 206 hours total leave," so she said - she contacted the university. After that I used the sick leave.

MRS OWENS: So they made you use that up, and then the termination?

MS NIU: No. Before I received the letter, and after I received the letter I use the sick leave.

MS McKENZIE: And before you get the letter - - -

MS NIU: After I received what is the termination - this letter. Because I have so many days, and as I say, the lady from the union contacted the university - can I now stay at home and use this sick leave, so they said, "Yes, okay." So I think - later on I think really I'm really down - again is down. If I use my sick leave when I justifying that I got a sore back, straightaway have three months leave under my sick leave - don't use WorkCover, don't use anything, just my sick leave - I think maybe my back were better.

MRS OWENS: But you said in your submission that the university doctor would not approve your sick leave at that stage.

MS NIU: Yes. One day I ask, I said - because when I ask for the sick leave, I said, "I can't hang out the clothes at this stage, and my muscle spasm all the time." I said, "Can I have my owing sick leave?" She said, "Not today. Come back maybe tomorrow, give it to you." Now I was painful, I can't move. So I went outside - this is the first time I went outside to see the doctor, and not stick with her any more, because I said, "I have my own sick pay, and I'm really suffering this pain," and she still said, "No." She said, "Come back tomorrow," she think about it.

So I said, "I trust you, stick with you for such a long time, 18 months, and you just said, 'No problem, no problem' and my problem is getting worse." I can't even - now at home I wash dishes, my hand like this, I'm like this - pain still there. So at one stage I use what is called - what is called - what is a plate, you use once and throw it away. Start with these plates.

MS McKENZIE: The disposable?

MS NIU: Disposable, yes. I use these kind of things - use once, throw it away, because I cannot wash. At home I only have - I'm living with my daughter - two of us. Haven't got the amenities to cook, haven't got the amenities to wash, but even for the little things, I can't do. People look at me - healthy. I still talking a lot, going out places a lot, busy every day, and I just can't do this job; I just can't do it. They said, "No, nothing wrong."

MS McKENZIE: So did you get any WorkCover payment while you were away?

MS NIU: I did; after 18 months I did. In 18 months I didn't. After 18 months, when I was in pain, I went outside to see the doctor, the doctor give me "unfit to work". After that - - -

MS McKENZIE: Then you got the WorkCover payment?

MS NIU: Yes.

MS McKENZIE: After that - 12 months later, then there was the termination letter?

MS NIU: Yes.

MRS OWENS: At that time you got the payment, you didn't get into any rehabilitation program?

MS NIU: Is that - - -

MS McKENZIE: You know, to help you go back to work, sometimes they can get someone to make arrangements to help you go back to work.

MS NIU: Yes. There was a lady from some place in Brunswick, is called the hip rotation centre. They come in to see my table, my chair, and make up a task table - you know, how many things I have to do, and each week I have to - for example, the first week I wash 10 glasses - that's for example. So the next week 12 glasses, the next week 14 glasses, and the next week 18 glasses. I said, "You should make my pain go away first than ask me to wash more glasses, and my pain getting worse, so how can you ask me to wash more glasses than ever - what is a task or duty, going higher, higher." I said, "I can't do it." I have chore, three weeks - up, up. I have three weeks, I can't do it, so I stop.

MS McKENZIE: So no more.

MS NIU: Yes.

MRS OWENS: But normally they would send you off to somebody for physiotherapy and so on.

MS NIU: No.

MRS OWENS: Rather than go through all that rigmarole, they would have sent you off to - - -

MS NIU: There was one physiotherapist in the university, in the clinic, so I went to see him at the university, once a week, for up to 10 times. That's 10 times - 10 out of two months - yes, 10 times.

MS McKENZIE: And after that, no more?

MS NIU: The first time I went to see him, he said, "Your muscles are like rock. Why don't you come here to see me?" I said, "I don't know you are here." That's all. So that's an arrangement made by the rehabilitation centre. They write a letter to me, write a letter to him, the physiotherapist. After that, no more. When I received this physiotherapist, is already 18 months or 20 months later - after 20 months.

MS McKENZIE: After the - - -

MS NIU: Yes, after 18 months.

MRS OWENS: Usually with rehabilitation, they say the most effective rehabilitation is the rehabilitation that starts early.

MS NIU: Yes.

MRS OWENS: That's when you've got a much better chance of addressing the problem.

MS NIU: This is about six weeks or something, you know.

MS McKENZIE: But this was 18 months afterwards?

MS NIU: Yes, 18 months afterwards.

MRS OWENS: I think your story has been a very interesting one, so thank you for that.

MS McKENZIE: And it shows us about how important it is that people get proper information about - - -

MS NIU: Yes, I think really - and later on some other people said - because I'm complaining myself, the language is not good - English is not good, and they said, "No, not only you don't understand English. Even they speak English, the group here, they don't understand the law, so they don't know. It's not only your language is not good" they said "he doesn't know".

MS McKENZIE: Yes. They, I think, are all the questions I need to ask you. That's a really helpful submission to us.

MS NIU: Thank you.

MRS OWENS: Thank you very much. We'll now break.

MRS OWENS: We will resume. The next participant this afternoon is the Office of the Public Advocate. Welcome to the three of you. Can I ask you each to give your name and the capacity in which you're appearing, for the transcript.

MS TOMAS: I'm Natalie Tomas and I wrote a lot of it, which is why I'm here.

MRS OWENS: Okay, thank you, Natalie.

MR GRANO: I'm Phil Grano. I'm the legal officer of the Office of the Public Advocate.

MRS OWENS: Thank you.

MS OLIVER: I'm Sarah Oliver, and I'm a student currently completing my placement at the Office of the Public Advocate, and I'm doing a research project about people with disabilities in the correctional system.

MRS OWENS: How interesting. They have just thrown you in the deep end.

MS OLIVER: They have.

MS TOMAS: I offered her the opportunity for a new experience.

MRS OWENS: Yes, I think it's a great experience. Thank you, all of you. I'll hand over to you, Natalie. You are going to introduce the submission that you say you wrote.

MS TOMAS: Part of. I just thought I'd summarise basically what was in the submission, and I wanted to say that I'm really happy to come here to be able to speak to it. I know that Cate knows what the office does but, for the benefit of those who don't, the Office of the Public Advocate has a statutory obligation to protect the rights of people with disabilities, particularly from exploitation, abuse and neglect. That is constituted under the Guardianship and Administration Act of Victoria 1986.

The three areas that we covered in our submission were based on the objects of the act - namely, effectiveness of the Disability Discrimination Act in promoting recognition and acceptance of the rights of people with disabilities; equality before the law and the cost-effectiveness of the Disability Discrimination Act in light of those two areas. As we indicated in our submission, the Public Advocate recognises the effects, the positive effects the DDA has had over the last 10 years in promoting the recognition and acceptance of the rights of people with disabilities. That's a mouthful.

To further enhance this objective of the DDA the Public Advocate has recommended in our submission to the Productivity Commission that there are benefits to acknowledging an organisation's compliance with the act through having a disability action plan in place; that the DDA should remain the stand-alone act rather than become part of omnibus human rights legislation. The main area that we talked about in our submission was equality before the law. The Public Advocate believes that this object of the act is crucial.

However, people with disabilities currently do not have full equality before the law. Therefore the Public Advocate believes that the effectiveness of the Disability Discrimination Act needs improvement in the following areas: there should be greater legal and financial resourcing of people with disabilities and those who support them, to use the legislation effectively and that the treatment of people with disabilities in the criminal justice system require marked improvement. The area of disability specific accommodation and support services are currently exempt under section 45 of the act from actions around disability discrimination and we believe that this is inequitable before the law. There needs to be stronger mechanism for enforcing sanctions for noncompliance with the Disability Discrimination Act.

The last area that I want to speak briefly about is cost-effectiveness of the DDA. The Public Advocate is of the view that both direct and indirect costs of complying with the DDA are small - that is, for organisations and individuals - and existing provisions for claiming unjustifiable hardship are more than adequate to minimise any indirect and direct costs of compliance and these provisions for claiming unjustifiable hardship shouldn't be further extended and, lastly, that the Commonwealth government itself should not be able to claim unjustifiable hardship under the DDA, which is currently the case.

So to conclude, and I hope that's five minutes, notwithstanding any of the above suggestions for improvement, the Public Advocate believes that the DDA is a vital piece of cost-effective legislation that is a positive force for change in the life of people with disabilities. That's it.

MRS OWENS: Perfect. Well-timed. I think it might have been slightly less than five minutes. Do Phillip or Sarah want to add to that?

MR GRANO: We thought we would probably approach this by seeing what questions you had and see if there are particular things you want to pursue with us. We've outlined the things we think are important.

MS McKENZIE: Can I do my usual barging in, and begin. Can I ask first about the question of participation in the justice system. Do you want to say a bit more about the respects in which there are difficulties for people with disabilities, and then do you want to suggest how the DDA might - perhaps with changes - address these?

MS OLIVER: The phases that we've been looking at have been particularly pre-court, court, in the corrections system and post-release. At each of these stages people, particularly with a mental illness or an intellectual disability - more so than people with a physical disability - are coming up against hardships in relation to these areas. Some of the issues that are problematic are the fact that people who have, for example, an intellectual disability often don't understand what the police are questioning them over. More often than not they'll quickly agree to what is being said to get the attention away from them, or because they don't want to show the police that they don't understand. This, of course, is a major source of concern for us.

Particularly what I've been looking at is the fact that people with an intellectual disability or a mental illness are overrepresented within the criminal justice system. At the moment that's not just because of a lack of services within the criminal justice system, but also a lack of coordinated services preventing them entering the criminal justice system on top of a lack of coordinated services helping them and preventing the reoffending rates which are occurring. What we've found in some of the research we've looked at is that, for example, people with an intellectual disability who are committing crimes - it's not their intellectual disability that is making them commit a crime. They have quite a similar background, so to speak, to the mainstream prison population in terms of lack of services, maybe a broken home, other offenders within the family. Would you like me to keep going a bit on the statistics?

MRS OWENS: Yes, if you've got some.

MS McKENZIE: It's very useful to have that material on the transcript.

MS OLIVER: At the moment it is really hard to know exactly what the representation is of people with disabilities in the correctional system, because one of our major sources of concern is the fact that the screening processes seem grossly inadequate. Currently Corrections Victoria is looking at having a much more thorough assessment process in relation to people with an intellectual disability or a mental illness, or for example, dementia or an acquired brain injury. However, when this was implemented we're not sure and, at the same time, it's still not addressing the issue of people that have been given a sentence of six months or less, for example. So we're concerned that there is this gap that people could be falling through. Another issue that comes up is that - - -

MRS OWENS: Just before you - this screening process, are they going to try and assess these people in some way?

MS OLIVER: Yes.

MS McKENZIE: Is it on reception?

MS OLIVER: Yes. A tier 1 and a tier 2 assessment. Tier 1, I think - this is off the top of my head - is looking at their risk and need assessment and a tier 2 assessment leads them into an offence specific program for example - if they have been committing sexual offences for example. Another issue that we've come across is the fact that - for example, for someone with an intellectual disability or a mental illness - for example, to get parole. It's quite difficult because they often don't have the resources or the social supports or networks, or housing for example, to receive parole. What you often have are people who have a disability that are in the corrections system who are actually serving greater times in their sentence than the mainstream prison population.

MRS OWENS: Are there any statistics on that? You don't have to present it all now, but if there are statistics - - -

MS OLIVER: There are, yes.

MRS OWENS: - - - maybe at some stage it would be very useful for us to have it.

MS OLIVER: What I will be able to do is send you a copy of the report that I'm doing at the moment.

MS McKENZIE: What is the time with that?

MS OLIVER: That will be ready hopefully by - it has to be ready by the beginning of October because it's being presented at the mental health and law seminar that is happening in Sydney in October.

MRS OWENS: That would be great. It probably won't help us with our draft report because we are due to have that out in October, but it will help inform our final report.

MS OLIVER: Absolutely.

MS McKENZIE: Can you speak to any of the statistics at the moment, or not yet?

MS OLIVER: In relation to the representation of people in the criminal justice system?

MS McKENZIE: In relation to the representation and this question about serving longer sentences because there are not the arrangements that they can make to go.

MS OLIVER: That's an area I'm really interested in at the moment. Certainly the framework report that occurred from New South Wales has a lot of information in relation to that, but that again is New South Wales.

MS McKENZIE: The same thing applies in New South Wales, does it?

MS OLIVER: Yes, absolutely. At the moment I can't find you any statistics, but I can certainly get them to you within the next week, if you need them.

MS McKENZIE: That would be very helpful.

MRS OWENS: Any statistics you can get to us early would be terrific, because then we can use them.

MS OLIVER: Yes, I can do that for you.

MRS OWENS: Even if we can't get your full report.

MS OLIVER: Yes.

MS McKENZIE: Thank you.

MS OLIVER: No problems.

MS McKENZIE: How can we sort this out? I mean, is there anything the DDA can do to sort this out, or are there some other alternatives that you would be recommending?

MS OLIVER: I'm not sure - Phil is probably better off to answer something like that.

MR GRANO: The issue around the DDA in this area is the effect of disability discrimination in the prioritising of government funding, which is outside the parameters of the DDA, but nonetheless if the DDA were - if the government were subject to ensuring that people who have a disability are properly treated before the law as a priority, like all other priorities in government funding, then we would see that it is discriminatory at that level, that people do not have access to justice. I haven't made myself very clear, have I, on that? Can I have another go?

MRS OWENS: Yes. Actually you made one important point, but then there is this other issue that some prisoners are going to be treated better - in inverted commas -

than others, so there is some potential discrimination under the act.

MR GRANO: It does work like that. Because people who have a disability aren't given the resourcing that they need in order to negotiate the prison system, then they are treated less favourably than prisoners who don't have their disability, within the prison system. That operates at various levels within the justice process. To eliminate the discrimination there has to be the provision of resources by government to people who have a disability, in order to access the justice system. That lack of provision of resources, in our submission, is less favourable treatment.

For instance, a person who has a disability will get some benefits in relation to getting legal aid. So if you have a cognitive impairment it is one of the special measures, special aspects of your case that they will take into account in order to determine whether you will get legal aid or not. However, because the other things - such as your amount of money you've got in the bank - will disqualify you, then the fact that you have a disability often doesn't mean very much in order to obtain legal aid funding for your case.

MS McKENZIE: So if you were a bit wealthier than the threshold, it doesn't matter whether you've got a cognitive impairment, you won't get legal aid.

MR GRANO: That's right, but the cost of disability in many aspects of life - not just at that human level, but at a financial level - is much higher than for a person who doesn't have a disability. So the fact that they've got a bit more money in the bank because, you know, they've got also a lot more in the way of expenses and those sorts of things, too, is not taken into account. So accessing the justice system, even at that level of getting legal aid, is very difficult for a person who has a disability.

MS McKENZIE: What about the question of the disadvantage suffered by - in particular people with intellectual disability or cognitive impairment - when they are appearing as witnesses or as defendants or when they're being questioned by the police? There were matters were raised about not understanding the questions, saying yes when really they don't mean yes, but just to get the attention off them, and so on.

MR GRANO: They are difficult questions to address and the independent third person program was introduced to address people being interviewed by the police. How well it operates is hard to say, whether it's been effective to actually enable people to exercise their rights such that they can protect themselves if that's what needs to happen. We would hope that it is, but it's a program that runs on volunteer services from people. It's not a fully funded program. There are, I think, still difficulties with the way in which people, even though they may know their rights, are still able to exercise them, and I'm not sure that we've done enough to enable people to actually exercise the rights, even once they've got to the point of knowing what they are.

MS McKENZIE: The independent third-person program is basically to have someone else there. Is that how it works?

MS TOMAS: Yes.

MR GRANO: Yes, at the police station, to give emotional support and to help the person understand the questions that are being asked, and their rights. But they're not there to provide advice. That's beyond their role.

MS McKENZIE: Has that been tried in courts - a similar approach?

MR GRANO: In courts you have the court network program, which is designed to help people negotiate the court system, and court networkers do have some training in disability issues. But I still think the courts are very difficult for people who have an intellectual or a cognitive disability, to access. Also the Magistrates Court is developing, and has here in Melbourne, a disability coordinator that really - yes, Ann Condon, who is there - but technically I think she can only come in once a person has plead guilty, although I think she might do more than that - I think she tries to assist people beyond that. So there is an effort being made, but I still think there are problems of helping people negotiate what is a fairly intimidating process, and you've got the added burden of finding it difficult to understand or to hear, or to concentrate, to participate in that process.

MS McKENZIE: Should the DDA be amended - you see, at the moment the objective about equality before the law is there, but the only substantive provision that directly relates to equality before the law is the one that deals with the administration of Commonwealth programs, arguably. Should the DDA be expanded in some way, to pick up these access to justice problems?

MR GRANO: Well, we believe it should be, because then there's an incentive for government to do more about these particular issues. They're difficult issues. I don't pretend they're simple issues, in that for a person with a cognitive impairment to be able to access the courts in a way that fully accepts and facilitates the exercise of their rights, it will take a lot of work to do that. But because this is terribly important - it could involve either their good name, their reputation, whether they go to gaol - it is something that deserves really high standards from the community.

MRS OWENS: So what could be done in the act? Any ideas?

MS TOMAS: I think - I knew I was going to be asked that question.

MS McKENZIE: What about treating it as a service? But you'd have to treat it as a service by the state. You've got difficulties as far as the courts themselves are concerned, because of the judicial immunity.

MS TOMAS: I think it needs to be spelt out, because at the moment what we're talking about is effectively indirect discrimination because of the way the system works. In theory it's supposed to be a level playing field, that everybody has the same processes and procedures to go through, but we know that it doesn't, because disability issues are not taken into account. So in some ways it needs to be - what you need to specify is how the indirect side of it needs to be applied to the criminal justice system as well, and how they need to take this into account, rather than - I don't think it's a matter of making a special provision for it, but just making it much clearer as to what individual service systems obligations are - if that makes any sense.

MS McKENZIE: Yes. It is a difficult area, but I understand where you're coming from.

MR GRANO: I suppose - the court buildings are subject to the DDA.

MRS OWENS: In terms of access - physical access.

MR GRANO: Yes, physical access. The processes by which a person gets before a judge similarly should be subject to the DDA, so that it's not just about what happens in the courtroom, but how the person actually gets into the courtroom and how that is facilitated. Those aspects surely should be subject to the DDA as well. So that if a person wanders into a court and they can't read, or they can't work out which court they're in, there should be ways in which that process is facilitated.

If they can't understand their rights - admittedly, if that becomes known - then a judge can take that into account in determining the value of the evidence before him or her, because the person didn't know their rights and was not able to exercise them. But I think it also could be important that there be an incentive to those who are collecting evidence or doing that aspect of it, to be aware of the Disability Discrimination Act and how steps need to be taken - as Natalie says - to put this person on a much more level playing field than they're currently on.

MS McKENZIE: The next matter concerns special services - you know, special services for people with disabilities. Am I right in my understanding that you'd like the exemption that relates to that matter to be removed?

MS TOMAS: Well, I think what we were saying, that because of the exemption there is no incentive or ability for people to complain about disability-specific services actually segregating them because of the disability - that you actually can't complain about something if you're not actually compared to the rest of the community. So that, in a segregated service, a whole lot of things can happen which are not equal to the rest of the community, but you've got no avenue for complaint at the moment.

MR GRANO: It's made a little more complicated, I think - because you have no comparator, and I think - is there a case which says something like, "You have to be compared to a person who doesn't have a disability" - whereas in the past, when the DDA first came out, we used to give advice that - it was compared to someone who didn't have your disability. So you could be compared to someone who had a disability, but not your disability.

Now, I think there's a case which says, no, you've got to be compared to someone who doesn't have a disability at all, and I think that's an unfortunate interpretation of the act. One case that I was involved in, where a person was in a community residential unit, they had both the same disability - an intellectual disability - as everyone else in that unit, but they also, as a result of another aspect - autistic spectrum disorder - had behaviours that led to their being treated far worse than anyone else in that house.

So the difficulty of running a DDA claim was, well, we couldn't compare this person to someone who didn't have a disability, because all the people in this service had a disability. But she was the only one who actually had that particular other disability, the one by which she was being treated less favourably, and it seems to me that's incredibly unfair.

The other aspect of this is going back - it's like again the government policy aspect around this. If government isn't required to put resources into disability accommodation so that people who have a disability have similar accommodation outcomes to the rest of the community, then we would see that as discriminatory. I think that's part of the problem, that the act - the special measures provision - makes it more difficult to argue that, for instance, if I built an institution for people who have a disability and they don't move into the community as a result of my building an institution, is that government policy to which I can complain under the DDA, or not? We would think it should be something about which a person should be able to claim discrimination under the DDA.

MS TOMAS: And once people are in that situation - if you look at the promotion and recognition of the rights of people with disabilities to participate, if people actually say that, "Because of your disability, you can't go and live out in the community and you must live in this institutional environment," that automatically means that people aren't going to be given the same opportunities, to develop the same opportunities to do other things that other people in the community are doing, but they're actually being discriminated against because - they're actually being told, "Because of your disability, you can't go out and live in the community," so they're being segregated away and being denied their rights to fully participate.

Because of the way the act is designed, you can't actually complain about that, even though it's a basic diagnostic medical assessment which - because there is no incentive for people to try a lot harder to work out - to give people the supports, and they're protected already because the act exempts them, there's no incentive to do that. It's the same stuff around - community residential units are not subject to residential tenancy provisions, which means people with disabilities in community residential units don't have tenancy rights, because they're exempt under the - section whatever it is.

MR GRANO: 23 of the Residential Tenancies Act.

MS McKENZIE: So they could simply be ousted?

MS TOMAS: Yes. There's no protection around tenancy rights or anything like that. They're completely exempt from it, which further disadvantages them and is, in our view, discriminatory and should not occur. Because effectively it's their home, their accommodation, there's no reason why they shouldn't be subject to the same provisions.

MRS OWENS: That section 45 in the DDA that's exempt - you know, for special measures - I think it's been put in for all the right reasons, and that is to ensure that if people are receiving beneficial services, there can't be a complaint against that happening. So it's a matter of tightening up the act, so that we're not knocking out the potential for these other forms of discrimination to be dealt with.

MR GRANO: That's right. I think when it was originally envisaged it was - if I were receiving beneficial services under the act, then someone else couldn't complain that they were missing out on those services because they were beneficial services.

MS McKENZIE: Someone with a different disability, for example.

MRS OWENS: Yes. You see, I think that's what it's there for.

MR GRANO: That's right, though that's not the way it's being used. It's being used to prevent people who are receiving inadequate services from complaining about those inadequate services.

MS TOMAS: And for decisions that have been made about their lives, which affects their complete futures - not being able to complain because, "Well, you've already been assessed at this level, you've already been assessed as not being able to live out in the community" or, "You've already been assessed as having to have this service," and there's actually no incentive to actually improve anything, because you don't have to. If you want to use the competition thing, there's no competition with anything else, because you don't have to prove anything, so you can just leave the situation be, without any need to justify what you're doing, and that leads to abuses.

MRS OWENS: We're just having a little check.

MS McKENZIE: I've asked a number of questions. I'm just telling Helen that I think I've done my dash.

MRS OWENS: It's very unlike Cate to do her dash. You did talk about the lack of formal sanctions in the DDA.

MS TOMAS: It's one of my pet hates.

MRS OWENS: I just wonder - you didn't really expand on that earlier. I'm wondering what else you would put into the DDA. Would you give HREOC greater power to, say, monitor standards - apart from initiating complaints - monitor action plans?

MS McKENZIE: Terms of imprisonment and fines for discriminatory respondents?

MS TOMAS: Well, I would go for the fines myself. Because at the moment a respondent doesn't even have to turn up to a conciliation hearing; there's no compulsion. It's all on the person who makes the complaint to present their case, and there's no - like, in any other legislation, you get told, "You've broken the law," then there's an immediate - even if there's not a legal process, there's a fine or something - you know, people actually take it seriously.

I think this probably applies across the board, but with the DDA you have to present your case, the respondent can choose not to turn up, so then it comes to the complainant's decision whether to go ahead to Federal Court or wherever - or take it any further. There's no fines for non-appearance, there's no fines for actual direct breaches. So, yes, you can conciliate and mediate and do all of those things, but while it's a very valuable act, I don't think there's enough teeth in it, in that area. I think there should be far more sanctions. People should be as afraid of breaching the DDA as they are of any other piece of legislation - you know, you know you don't do certain things because you'll get a whopping great fine, or when it's pointed out to you, you suddenly decide to turn up.

MR GRANO: Have there been any prosecutions of people and fines imposed as a result of, say, victimisation, under the act - for a finding of victimisation?

MS McKENZIE: Not to my knowledge. That's something we should ask HREOC perhaps about.

MS TOMAS: Because there's a penalty for that under the act, which is a very severe one. I was quite surprised - pleased, too. But, I mean, you have to put a lot of work in to even get anywhere near that.

MR GRANO: That would need to be a prosecution move by the police, so you would have to engage the police to say - and then you would - that would be a higher standard of proof, I suppose. Is that the way it works?

MS McKENZIE: It should. What I'm not certain of, and I'd have to go and look at the HREOC Act, is to see whether the commission or an officer of the commission can also institute a prosecution for proceedings like that. But my recollection is, no, I don't think they can.

MR GRANO: I presume that would need to be before a court rather than before the commission itself.

MS McKENZIE: Yes.

MS TOMAS: Which raises the whole issue of costs, which is another thing we were talking about, about the costs of actually going to take out a DDA claim. Because even though in theory it's not supposed to cost you anything at conciliation stage, you're advised to get some sort of legal advice. Whether that's DDLS, for example, in Victoria - the Disability Discrimination Legal Service - or a community legal centre, they're incredibly under-resourced and will only take cases that meet certain criteria. So it depends on whether you have - as the pamphlet I was reading the other day said - whether you can cope with the stress, the costs and the time it's going to take, apart from everything else that's happening in terms of the discrimination.

So there's a great disincentive for anybody with a disability to actually make a complaint because of all those factors, and the fact that if it's not conciliated, then the only thing you can do to - or even if it is conciliated, the other side doesn't have to abide by the ruling, so you have to go and enforce it, which means you have to go through the court and even though Federal Court in theory usually doesn't award costs against the person bringing it, there's always a risk, and the fact that - you know, people with disabilities have enough financial cost without having to cover legal fees as well. So you can actually be in a double bind. It's a real disincentive to actually do anything, because the resources aren't there.

MRS OWENS: So those sanctions you talked about before, if somebody doesn't abide by the conciliation result, would you say the sanctions should apply at that point as well?

MS TOMAS: Yes, well, I think so. Phil's not - I mean, I do, yes.

MR GRANO: We haven't really discussed it as an office position, so I can't put what the office would consider. But tightening up the processes of enforcement, and also, I think, where people perhaps don't want to bring a complaint, but there is a genuine grievance that would - for instance, like victimisation - lead to a prosecution, where that could be possible, whereas at the moment, I imagine, the police wouldn't even know quite what a victimisation complaint under the DDA would look like to bring it to a court in the first place, and what level of proof and so forth would be required.

I think different options would be good, if there were various options available to people, apart from just the complaint process, but through a civil complaint under the act, whether these other options are actually real or whether at the moment they're somewhat theoretical.

The other thing we want to push very much is that these things we're saying - they're not so much criticisms of the legislation, because we think the legislation has been terrific in the way in which it has facilitated access to the community. So it's around - again, this particular one - around going to an under-resourced disability advocacy legal service, is because it's an access to justice thing. It's about government properly resourcing people to be able to participate in the community, to use the rights that are under the DDA. So that for us is not so much about the legislation, but the support for the legislation.

MRS OWENS: Do you think there should be some sort of standard that's applied in this area of access to justice? I mean, we've got a transport standard, there's been work done on an education standard, there's been work done on access to premises standard. Would it fit into this area or not?

MR GRANO: I think there could be some idea of bringing around the standards in relation to access to justice. But I imagine - I'd probably need to think about that more, in that standards can have a bit of a double effect. Standards, once a person has met the standard, means they can then say they haven't acted in a discriminatory way. But given - if you look at the whole circumstances, it still might be less favourable treatment. So standards may take you so far, but they still may not resolve all the issues that we need resolved. So I wouldn't first of all look at standards. I think it's more about proper resourcing, and a commitment by government to resource so that people can actually exercise their rights under the act.

MS TOMAS: And that's resourcing around legal support, but it's also resourcing around other supports they might need in order to participate. You know, the commission tries as hard as they can, but I mean, there's only a certain amount they've got, so people actually need a lot more support to actually understand what's going on. I know a lot of advocacy groups try and do that, but they don't have the expertise, and it just takes a lot of time and effort, and that again discourages people. So we need a whole lot of supports apart from the legal ones, to make it really accessible to people.

MRS OWENS: You won't be surprised to hear this as well, that we're getting a lot of submissions and a lot of people have been talking to us about this whole issue of resourcing, and it's about resourcing HREOC appropriately to carry out its functions, including its education functions, its accessing legal aid groups, its accessing advocacy organisations, its resourcing schools, for example, to be able to enrol students with disabilities and provide the same degree - the necessary degree of support aids in schools, which we'll be hearing about in a minute. So we're getting this picture of under-resourcing coming from all angles.

MR GRANO: And I guess, because we were created through the act, we have legislated that people who have a disability have the same rights as everyone else in the community. That's our legislation. Then we have an obligation to make it happen, by putting dollars behind it, and that's a large frustration with the policy and the fulfilment of this legislation.

MRS OWENS: That might be a good place to finish, I think. Are there other issues that you wanted to raise with us? Sarah, it was very valuable having you here.

MS OLIVER: Thank you. I'll forward information on to you anyway.

MRS OWENS: Is there anything else you wanted to say, Natalie, about the submission?

MS TOMAS: I think we've pretty much covered the main things that we wanted to talk about, and thank you again for letting us come and talk to you about it.

MRS OWENS: You've been very helpful, both of you - all of you in fact, for the oral submissions and discussion. It has been really helpful. Thank you. We'll just break for a minute.

MRS OWENS: Okay, we'll now resume. The next participant this afternoon is the Association of Independent Schools of Victoria. Welcome to you all. Would you like to each give your name and the capacity in which you're appearing today, for the transcript.

MS RICHARDSON: I'm Katie Richardson and I'm here today on behalf of my daughter Emma.

MS KERSTEN: I'm Therese Kersten, I'm the special education officer at the Association of Independent Schools.

MR ROSS: I'm Alan Ross, I'm a board member of the Association of Independent Schools of Victoria and also principal of Billanook College, a school in the outer east, with a considerable number of Commonwealth and state funded integration and special needs students.

MRS OWENS: Thank you. And we've also got Emma Richardson sitting there who is a student.

MS E. RICHARDSON: Hi.

MRS OWENS: She's here with her mum and we saw her grandfather this morning. So thank you very much for coming and I'll hand over to you, Alan, I think initially to make some introductory comments on your submission.

MR ROSS: Thank you very much. The Association of Independent Schools of Victoria - AISV - was established in 1949 to represent and promote the interests of Victorian independent schools and provide services to them. More than 97 per cent of all independent schools in Victoria are members of the association. That's more than 200 schools educating 100,000 students in Victoria. Individual schools are individual legal entities and the association is not a system authority but is a nonprofit service organisation to the members. As part of this role the association represents the interests of its member schools to governments and the community on a wide range of issues, including this one.

The area of special education is becoming increasingly important to our sector and therefore to AISV. In fact students with disabilities are an integral part of the independent school community. 160 schools covering 171 campuses educate 1400 students with disabilities. At my own school there are 48 integrated students in receipt of Commonwealth funding and 44 students in receipt of state support services funding. AISV welcomes the commission's Disability Discrimination Act inquiry as a mechanism by which governments and the community can work towards the important goal of expanding the opportunities available to all people with a disability.

After I've made a few comments, Therese Kersten, AISV special education officer, will highlight the growth in students with disabilities attending our schools, and Katie Richardson, a parent with a student with a disability, Emma, will speak about her experiences in the family. In coordinating our submission to the inquiry, AISV sought to address the three objectives cited in terms of reference 3(b) with particular relation to students with disabilities and their experiences with independent schooling. In each instance it becomes obvious that the achievement of these objectives is inhibited by discriminatory funding practices that impose limitations for parents who are seeking out the most suitable school for their child's individual needs.

If we are to eliminate - and I quote from the act's objectives - as far as possible discrimination against persons on the grounds of disability, we cannot allow a situation where students with disabilities are discriminated against based on the choice of school, especially since this choice is often determined by the nature of the child's disability and the needs associated with that disability. Similarly, the act's intent to achieve equality between people with disability and others cannot be assured until we provide all schools with the resources that allow it to educate all students on a level playing field, nor can we promote recognition and acceptance of the rights of people with disabilities if it is harder for parents of a disabled child to choose their school than it is for parents of a non-disabled student.

Unlike government schools where the cost of the act's implementation is fully met by governments, independent school communities must absorb the costs associated with implementation. At Billanook, for example, the cost of hourly sessions for visiting teachers and therapists is $80 and the state support services allocation is $17 per hour. This big difference between these sums is made up by the school, and other schools in the independent sector face exactly the same funding dilemma.

The low level of funding available hinders the scope of the independent sector's ability to educate students with disabilities. Parents are often shocked to learn of the independent sector's lack of government assistance in reference to students with disabilities. The difference in funding arrangements is obvious for parents who move their children from the government sector to the independent sector. According to research undertaken by the association by Irving Saulwick and Associates. 74 per cent of respondents said that students with similar disabilities should receive the same amount of government money regardless of the sector in which they're educated.

AISV strongly believes that the funding arrangements that allocate support base on school sector, rather than the need, fail to support the DDA in meeting its objectives and reaching its full potential. Because the disparity in available funding is most obvious in the state government's funding arrangements, our submission placed particular emphasis on the inequity at the state level. The inequitable funding arrangements detailed in our submission are obvious when students move between sectors. While a child in the government sector may have been receiving between $4001 and $30,536 in additional support, he or she will lose almost all of the state government funding upon enrolling in the independent sector.

One family that recently inquired at Billanook decided not to go on with the enrolment because their son is currently receiving 23 hours of funding per week in his government school, whereas at Billanook he would not be eligible for any funding at all. Many enrolments of students with disabilities in independent schools, particularly independent special schools, result from a government school recommending their school to a family - table 4 page 13 indicates that. For example, Berengarra School, 69 per cent of their students; Currajong, 60 per cent and so on.

Though the child's needs have not altered, the amount of support when they change sector provided declines dramatically. Furthermore, the annual funding provided to the government school for this child's needs remains with that school, even when the student moves to another sector during the same year. We would contest that this funding arrangement doesn't place paramount importance on the student's individual need. In a sense, the success of the DDA has amplified the difficulties with current funding arrangements, so while there's been an increase in the number of students with disabilities enrolled in the independent school sector, the next challenge is to better equip these schools with the resources that complement their willingness and eagerness to provide the best education possible for their students.

At my own school, numbers of students in receipt of Commonwealth funding have more than doubled in the last four years. In 2000 there are 21 integration students who were receiving Commonwealth funding; this year there are 48, and the inquiries continue. Our submission clearly shows that the DDA's intentions have not yet come to fruition for all students with disabilities and their families, particularly those who seek to enrol their children in independent schools. If a student is able to flourish at a particular school despite their disability, parents and school communities are left with little choice to make the necessary sacrifices that will enable the student to reach his or her potential. This desire comes at enormous cost to schools and their communities.

At my school, five families of a total of 40 who were inquiring about enrolling at the school have decided that the lack of funding available will preclude them from enrolling at the school, even though Billanook is their school of choice. They decided to remain in the government sector where they receive full support. There clearly exists a need for governments to support the implementation of the DDA. Only then will its enormous potential be realised for the families of students with disabilities who choose independent schools. Therefore our submission did not seek to recommend alternatives to the legislation but to instead find ways that will better support the community in meeting the DDA's objectives. As such, it is critical that governments ensure that all children receive adequate and equitable disability assessments, financial assistance and support services.

Our recommendations for resourcing equality included recommendation 3, that the costs of implementing the DDA are more adequately supported by governments, regardless of the sector in which the students attend school. Recommendation 4, that all state and territory governments accept responsibility for the provision of disability assessment reports for all children deemed to be in need of assessment. Recommendation 5, that the government tags a proportion of state's GST funds from 2008 for the purposes of providing equitable levels of funding assistance and support services to students with disabilities in government and non-government schools and that this is based on the level of resources each state provides to students with disabilities in their government schools.

Finally, recommendation 6, that the federal government explores the introduction of a limited tax deduction of $1000 for gifts of a recurrent nature associated with the education of students with disabilities. I think I'll leave it there and Therese Kersten can outline some of the social benefits of students with disabilities attending independent schools, and current funding arrangements.

MRS OWENS: Thank you.

MS KERSTEN: Thanks for the opportunity to present today. It's been great. I'm here because my job involves day-to-day contact with the independent member schools, and families and students with disabilities in Victoria. I've been in this role for 10 years and I came in when the DDA first started, so it's really nice that I'm still here when you guys are looking at the DDA and its implication, it's great.

MRS OWENS: Actually, in another way it would be really nice if you didn't need your job now and it wasn't an issue.

MS KERSTEN: Precisely. Well, part of my job is not only to wade through the funding debate but also to assist our schools in understanding the DDA when it came in. I think in the 10 years that I've been there we've seen not only a large number of increasing students with disabilities but a large number of communities and schools, and particularly principals, who now have a clearer understanding of the DDA and its intent.

The evidence that we've got is just phenomenal as far as the increase of number of students go. When I first started in 93 I funded 338 kids, and now I fund over 1400 that are currently in independent schools. We allocate Commonwealth and state funding, and as Alan pointed out, it is the inequities within the state government's funding in Victoria that we're most concerned about, for our schools to do their job well with their students. The social benefits are enormous for schools, not only for the 1400 students with disabilities but also for the more than 100,000 non-disabled students that are in our independent schools. It's vital that the students with disabilities have access to the independent sector and to the school of their choice, but it's equally important that the independent sector has access to people with disabilities within their community.

Quite often I get frustrated principals on the phone who really want to accept an enrolment of a student with a disability, not just because they're disabled but for a whole number of reasons, but the financial constraints to meet the needs of that student is what hampers their decision and makes it difficult for them. One vice-principal of a large mainstream independent school recently said to us:

> Our non-disabled students have benefited enormously by working alongside students with different needs. The involvement of students with disabilities in our mainstream school enhances acceptance, knowledge and tolerance and this is a very positive benefit for our school community at large.

So the implementation of the DDA has had an enormous social impact on schools from what I can see. But what's really limiting that and restricting that and causing difficulties in schools is the issue of funding resourcing. I came in at the last presentation that you had and I see it's quite a common theme that's been across to uphold the true ethos of the DDA. It's the funding and resourcing issue that's hampering schools and other agencies in doing that.

The upward trend of enrolment is a significant financial strain on our school communities; unlike the government schools, as Alan said, where they can tap into government resources and the kids are supported. We've had approximately 250 per cent increases in enrolments of children who are eligible under the state support services, yet we've had a 30 per cent increase in funding. This is why, as Alan mentioned, the $60 an hour service, and they're gaining $17 an hour. The reason they get the $17 an hour is not that the state government has said, "That's all you're getting." Basically what they say to us, "Here's your bucket of money," and the AISV board has always had the premise of assisting all students that are eligible, so basically we share it across the students.

So the ever-increasing number of students and the almost stagnant bucket of funding is causing the level to drop down to $17. Some people are having to purchase their services at 80 or 90 dollars an hour so I think your 60 is pretty good.

MR ROSS: We're closer, I think.

MS KERSTEN: Yes. Well, in some cases it's quite high.

MS McKENZIE: So they give you - I'm sorry to interrupt you.

MS KERSTEN: Go right ahead.

MS McKENZIE: So they give you a bucket of money based on the numbers of enrolments.

MS KERSTEN: No, with the Commonwealth funding it's based on census information. With the state government funding it's based on a survey that the state government undertook in 1995 on visiting teacher services available to independent schools. Just prior to 1995 there was a union ban placed on independent schools of government visiting teachers actually going in there and working. Prior to that there was available resources of visiting teachers that independent school principals could tap into. They shut down those school support centres. They then did the survey and asked our schools, "All right, how much service have you been getting from the visiting teacher service?" Three things: a busy principal doesn't always have time to fill out a survey, so they didn't get a full response. The second thing was some of the schools had never seen a visiting teacher because of the union ban that was placed on them and the third thing is, some principals were so busy they didn't know where the school support centre was and it was a government service that they didn't believe they could tap into.

So the survey that they did in 95 actually defined the bucket of money based on the needs of our sector. Annually we have asked them to resurvey our schools and they haven't. We've actually done it ourselves this year through an agency and we're about to present that to government shortly. So we're hoping that will make it clearer to them of the numbers of students that actually require the support and how much support they need.

MS McKENZIE: So the current bucket of money is based on the 1995 figures which are based on - - -

MS KERSTEN: An inaccurate survey.

MS McKENZIE: - - - an inaccurate survey and obviously on the numbers, even assuming for the minute the survey is accurate, but on the numbers of - - -

MS KERSTEN: In 1995 there were about 260 students that accessed that service. Now, with that state support funding it's closer to 1200.

MS McKENZIE: But it's the same amount of funding?

MS KERSTEN: It's grown by about 30 per cent, yes, CPI increase.

MS McKENZIE: It's 30 per cent extra and you just divide it by more.

MS KERSTEN: Yes, that's right. Therefore the first year we allocated it we gave $45 an hour for service and that was pretty good in 1995. But as the years have gone on and the number has increased it now goes down to $17 an hour.

MRS OWENS: But at the same time the state government is allocating funds into a bucket for the independent school sector, it's providing government schools with so much per child depending on the level of disability.

MS KERSTEN: Yes.

MRS OWENS: It's a more sophisticated funding arrangement.

MS KERSTEN: Yes, that's where we access our Commonwealth funding for that service based on the disability level. The state funding is for specific services like the visiting teacher of the vision impaired, visiting teacher for the hearing impaired and for the chronic ill health, as well as speech therapy. But the Commonwealth funding we run at exactly the same lines as the statement government does. We have the same criteria for eligibility. They have said six levels of funding, and as Alan said, it's $30,000-odd for the highest level. Because we're dealing with a much smaller bucket to begin with, our committee chose three levels of funding, 1, 2 and 3 thousand. Therefore we assist all eligible children in our sector, but the amount is reduced.

MS McKENZIE: Now you're talking about Commonwealth money at this point and when again you say the smaller bucket, is that because it's done again on the same 1995 figures?

MS KERSTEN: The Commonwealth money has always been deemed as supplementary funding and it used to be in their guidelines in 1993 that full responsibility lay with the state. So what they actually give to us percentagewise is the same as they'd give to the government sector and to the Catholic sector. So the Commonwealth funding overall is regarded as supplementary support. What happens in Victoria - and it varies from state to state, I guess you will be finding this out on your tour - is that each state government offers different amounts for different reasons. That's why we raise this issue of funding here because it's particular in Victoria.

I had a quick look at the transcript from the National Council of Independent Schools and theirs is very much a national response - they are the body - whereas it varies from New South Wales to Queensland to South Australia, but in Victoria here we just don't have access to that. So the supplementary funding of Commonwealth stuff is all that we have for the integration purposes and that's your aide support, your capital works, your occupational physiotherapy. But the other definite services are state funded but that's all they fund.

MS McKENZIE: But they're for specific services like visiting teachers and so on?

MS KERSTEN: Correct, yes.

MS McKENZIE: Whereas the government schools in the state get funded quite differently.

MS KERSTEN: They do. They're funded based on the child's disability level and needs and then it encompasses a myriad of services that they might require and it might be a bit of OT, and it might be some speech and it might be some aide time, whereas we're quite segregated in this because of the two different government bodies supplying the money. But the state funds are quite definite services. The Commonwealth money is called School Support Salary Support so it actually is much broader in its usage for schools, whether it's an aide they use to employ or whether it's a special ed teacher or a consultant or a psychologist or a counsellor. It's much more user friendly, if you like.

So I guess for us the funding is a real issue, the resourcing and seeing it from my point of view over the last 10 years watching principals like Alan and 200 others struggle with not only the moral dilemma but their school's ethos and philosophy of open-door policy and siblings of other students, particularly students who may have become disabled during their school period, who don't roll in the door like Emma did but students who, you know, have had an accident on the way. Principals really struggle with it because it is at the expense of all other students in the end. All their fees are increased so they can accommodate employing a special ed teacher, assisting with ramps, $50,000 to put a lift in. All these things they can make application to us for but because of the limited amount of funding they're never going to get what they need. So it's like the supplementary nature continues.

So it has been difficult from my point of view to watch these principals struggle with, "We want to enrol this child, we want to be able to support the needs of the child," and as you can see from our submission, our numbers are just growing and they continue to grow. I think schools have become quite clever and resourceful in their own nature, they've had to be, because they just don't have the luxury of access to resources. That is where some schools have denied enrolment to students and often I will get parents calling me and they're terribly upset about the fact that the school has said that they will not be able to cater for the needs of the child. But when you go through and explain, "This is what the school can access. This is how this school operates," they then understand.

Not all schools can claim that and I guess that's another issue we raised too, the case of unjustifiable hardship and how vague that is, and often schools will say to me if I'm giving them a talk on the DDA, "What is unjustifiable hardship?" But the whole act, the whole DDA is so individual and particularly with independent schools and our lack of access to additional funds we need to look at a case by case basis and not just when a disabled student is coming in. It's looking at the child, the needs of the child, the resources required and whether that particular school of the parental choice can provides those needs and in some cases, in quite a few, they can't.

So we have had a lot of dilemmas with families and principals who just say, "We really want to accept the enrolment but we can't." That is probably more socially demoralising for the school community. The child may be a sibling of other children that attend the school and they've seen the child come up and play in the playground and they're waiting for the child to enrol but the needs are so high and the resources aren't, and they often have to deny enrolment and that's quite heartbreaking in a lot of cases. But you can see that our schools have still struggled on and done the best they can.

It's almost - and I was talking to Kate before we came - that it's often the case where parents are so relieved - they've struggled all their lives with medical issues, with the whole gamut of things, that by the time they get to secondary school in particular they're just so exhausted. Sometimes I want to shake the parents and say, "No, come on, you've really got to keep going," because this is not how it should be for these kids.

MRS OWENS: One more fight, a big one.

MS KERSTEN: Yes, and they don't want to cause trouble because they think they might get kicked out or whatever. But I did note that in the Australian Education Union's submission to the inquiry that they claim that the Commonwealth SASO funding is biased towards private schools and I guess that - - -

MRS OWENS: I was going to ask you about that. I've got it sitting right here.

MS KERSTEN: I thought you might. We actually quickly read it and thought, "I bet they'll ask us about this one." The claim seems to have been made without comparing the total government funding that's available to each sector. That's where before, Kate, when you asked me before there's the state stuff, there's the Commonwealth stuff - students with disabilities integrated at mainstream independent schools receive the same recurrent funding as other non-disabled students and students attending independent special schools receive the highest state and Commonwealth.

But students attending both mainstream and special schools receive additional Commonwealth funding, and perhaps this is what the AEU is alluding to, which is $621 in strategic assistance annually. Now, it's often the case in the newspapers when you read about the additional funding that's gone to the independent sector $620 per student is the actual additional stuff per capita. Then they can access the targeted funding which I am involved in distributing and that's what I referred to about the state funding for the services and the 1, 2 and 3, 4 thousand dollars for the integration support. So by comparison students with disabilities attending government schools received between $4000 and $30,536 in additional support from the state government alone, whereas we don't have that.

But the whole issue about additional funding going to the private sector is quite limited if you actually break it down and have a look at it, so I think perhaps that's what they were referring to in their submission. Now, I know that in our submission to you we included a number of case studies and I guess - I know that you've read them.

MRS OWENS: Thank you for those case studies. We do like case studies.

MS KERSTEN: We're talking about people and that's our job and really from my point of view and Alan's point of view we're probably not the best people to be sitting here. It's people like Katie and Emma who have to jump through the hoops the whole way through their lives and find all the hurdles on the way and hopefully we can help them smooth it out. But one in particular and Alan highlighted the case of our special schools. We have a number of special schools that cater particularly for children with severe emotional disorders. In Victoria - and it's very much a Victorian perspective I talk from - there is no government alternative. So for the families of those students, and you may remember the case study in our submission from Currajong where a parent had approached 32 schools.

MRS OWENS: Yes.

MS KERSTEN: Because there is no government alternative for such high level severe social and emotionally disordered children the parent had no choice but go to an independent school and it's really important to consider the negative impact of this funding arrangement across the whole spectrum of not only our special schools but our mainstream schools, and I know that's what Katie will discuss is the parental choice issue. For these parents who really tried at 32 schools, it's heartbreaking to see that their choice is taken away from the start.

I did discuss the unjustifiable hardship stuff which we find difficult and it needs to be more clearly determined I think for schools. We didn't really touch too much on the standards and I was wondering whether you - because the previous people were discussing that. We've been involved with the educational standards for over seven years now, putting our input towards the MCEETYA decisions on that. We've found it not only a long and arduous process, but quite frustrating at times. It included everybody from the disability area from pre-prep through to tertiary which when you're sitting next to a government school person who can have access to funding and resources, who can make those decisions, they found it really difficult to understand my perspective that, yes, our principals are trying to meet these standards if they're implemented, but to be honest with you, they've got no way to meet them because it comes back to the funding and resourcing.

The standards themselves would be great as recommendations. But the fact that the independent sector has no means of meeting those standards because of the lack of resources is just such a difficult issue for our schools and I think that's probably one of the things that has dragged that committee out for seven years now. It's probably the longest decision-making process committee I've ever seen. It's a difficult area. I know that the standards came in quite easily in the Building Code area, that was defined and - but when you're making adjustment in curriculum for kids, how much does that cost and who bears the burden. Teacher training is one of our other issues that I see from my perspective when I try and deal with teachers in schools - and again this is a Victorian perspective. I was originally trained in New South Wales and in New South Wales it's mandatory at a university level to do at least one subject area in the disability field, whether you're going to be a special ed teacher or not.

In Victoria they offer great units in the area but it's not mandatory, so we get so many young teachers out who are good teachers, who will have a child with a disability in their class while they're teaching kids, yet they have no concept of how to deal with the child, particularly in the emotional area, behaviour problems. We've tried to address it our own end because we do some professional development with our teachers but it needs to come from the tertiary sector to skill these people up to work with students. I guess one area is - the way we try and do it is - the area of learning styles, to actually get teachers to understand their own learning style and to deliver lessons in a variety of learning styles that will accommodate everyone.

I've spoken to some of the universities here and suggested that you don't need the tag "special ed" because that will keep those teachers away that are not interested in that area. If you make it mandatory and it becomes learning styles, that will enable the entire class at different levels to learn. So it really is a hope of mine to see that the universities in Victoria take that on and make it mandatory because now that the DDA has been in for 10 years - I guess 10 years ago they could have said, "You might not have a disabled child in your class," but the DDA encompasses such a range of people who learn differently for whatever reason. I think it's well overdue now - 10 years overdue - that the universities actually encourage that for all teachers to teach the different learning methods, and then it doesn't become special ed.

That's for me probably the biggest thing when I try and assist teachers in accommodating kids in their class. I guess I see first-hand how the funding arrangements affect students with disabilities, and families. But yet I've seen in my 10 years the enormous potential of the implementation of the DDA and how it makes some people sit up, but it's also made some people just cheer, that it's just fantastic. But then again, as I said before, it's made a lot of people cry because they can't meet the DDA because they don't have the resources.

So the future depends on a high degree of government support for students with disabilities, irrespective of what sector they've decided to send their child to. I guess that's where I'll hand over to Katie now who will talk to us about the difficulties of choice for families.

MRS OWENS: Thank you. Thanks, Katie.

MS RICHARDSON: Well, I'm just here today really on behalf of Emma and to maybe give you a little bit of a background information on how our choices could be considered limited when it came to making the right decision for Emma and the secondary school she wished to attend. We as parents try and always do the right thing by our children. When Emma was in about grade 4 the discussions started about what school she herself would like to attend. Out of the schools that we mentioned, Flinders Christian College was the school of Emma's choice for a number of reasons - and they were her friends, were heading in that way; that it was a small school, and that going from a small primary school she would like to attend a small secondary school, and that it was a Christian school and she enjoyed her religious education and would like to continue with it. The government schools around us don't provide that religious education and Emma was in the hope that she could continue with her religious education.

So after much dilemma - as Emma attended a government school, we knew what her funding was at. It was a level 5 funded child at a government primary school and was receiving 23,000 plus which gave her full integration aid, speech therapy, physiotherapy and occupational therapy. So when the time came to inquire about attending an independent school, much to our shock we saw that that amount of money would be $3000 and that now Emma wouldn't get a full time aide and that her resources would be limited as in physiotherapy, speech therapy. So our dilemma then was, what do we do? Once again we put that to Emma and she still wanted to go ahead and sit the exam for Flinders Christian College and she knew that maybe at the end of the day we would have to reassess, which we thought was very unfair because she as a child should have that right of choice and we could see that sort of slipping away from us.

So we went down to Flinders Christian College and they have been more than helpful - bent over backwards with Emma. So Emma sat her exam, passed with flying colours. She also sat the two interviews needed with their principal, and the principal was very impressed with Emma's pass report and said these were the sort of children that they wanted at Flinders, Emma was the sort of child that they would like to have. So we all sat down again and discussed it with Emma and we realised that she would only get part-time help and that if her grades were to slip in any way that we would then have to reassess where she was at.

After six months and lots of hard work on Emma's behalf, Emma comes home from school, does her normal homework that's set for every child and then does her catch-up that she's missed during the day, because she hasn't got an aide there all the time to help with writing things down and everything else, but she's kept her grades up, so it just shows her determination that she wants to stay at Flinders.

MRS OWENS: Can I ask you, Katie - or Emma - how long does that take each night after school to do the homework and then all the catch-up?

MS RICHARDSON: Emma's routine: comes home from school, has something to eat, has a toilet, has something to drink and straight into homework. So by 4 o'clock Emma is doing homework; 6 o'clock comes along and it's dinnertime; it's dinnertime, bath time and then she has another half-hour's homework. So it's two and a half hours of homework each night Emma puts in. For a year 8 student we're told that between and hour and an hour and a half is the maximum that she should be doing.

MR ROSS: I wish I could get my students at Billanook to do as much homework as Emma is doing.

MS RICHARDSON: That, as I said, is Emma's determination.

MRS OWENS: But I wonder about the compounding effect by the time that you - Emma - get to year 10, year 11, year 12. I mean, the catch-up will be - I would presume, get longer, the later you are in the school program.

MR ROSS: Absolutely.

MRS OWENS: So by year 12 Emma will be going to bed at 1 o'clock in the morning if you're not careful.

MS RICHARDSON: We've also discussed that. At the moment, Emma does a secondary language. She does Indonesian which she can drop if it becomes too much time needed, so she can use those lessons at school to do a bit of catch-up.

MRS OWENS: But that's a pity. If other kids can do the second language and not have to drop it because they don't have to do the catch-up, it's a bit unfair, isn't it?

MS RICHARDSON: It is, very unfair. If Emma had an aide with her full-time which she did for seven years of her primary schooling, she'd be fine. I go to school two mornings a week to try and help.

MRS OWENS: So that means you're not working on those two mornings.

MS RICHARDSON: That's right. If it came to the end of the day that I needed to give up work for Emma to continue at Flinders, I would do that, because she's happy there.

MRS OWENS: That's also very important.

MS RICHARDSON: Definitely.

MRS OWENS: But that's a real sacrifice, isn't it?

MS RICHARDSON: It is, yes.

MRS OWENS: You're paying fees but then you're giving up work. I mean, I know the fees may not be that high but it's still more than you'd be paying if you sent Emma to a government school.

MS RICHARDSON: Yes.

MRS OWENS: So you're having to give up work as well.

MS RICHARDSON: Yes. Also when Emma received a letter saying that she'd been accepted, the look on her face was worth it, because we'd actually said to her - we had her ready to be not accepted for the fact that it was a lot for the school to take on a disabled student and also to be prepared that she may not make it into Flinders for a variety of reasons. So, yes, the thing is that we had to assess all of that and I think what made us come to the decision is it was Emma's decision and every other child I think gets that choice and we weren't going to take the easy way out for Emma. In reality if Emma had been able-bodied and had said that she wanted to go to Flinders we wouldn't have had all this dilemma to think about. It wouldn't be a second choice for us, we would have said yes straightaway.

So it's a bit of a worry that we as parents have to even come across that. As I think Alan mentioned earlier, there's probably a lot of parents out there who look at his school and other independent schools throughout Victoria and see that as the right choice for their child but at the end of the day they've had to make a different choice based on funding which is a real shame. I think education is an integral part of - in anyone's life and to have a choice is the main thing for any child. Really every day, as I said, Emma goes off to school. I see the children there are accepting of Emma. She's really fitted in well at Flinders. So we've made the right choice in that situation and I feel that for every parent they should have that choice.

Government schooling tends to get a lot more funding and it's terrible to think that the dollar rules what you decide on for your child. But you can understand why parents turn and make that decision because - - -

MS KERSTEN: It's easy - like you said to me before, Katie, your husband said - - -

MS RICHARDSON: Yes, he actually said - my husband and I as a family unit had the discussion and I said to him, "This is 23,000 that she'll get or it's 3000. She won't get the aide time, therefore she'll have to work harder. We ourselves - I will have to go and volunteer some time," and Rob, my husband, turned to me and said, "Well, wouldn't it be easier if we sent her to a government school?" "Yes, it would, it would be a lot easier but is that what we're going to do? I don't think so. It's her choice, it's our choice and that's how it should be, just like everyone else's." That's the decision we made. The Universal Declaration of Human Rights which I didn't state but they actually declared that a parent has a right to choose the kind of education that shall be given to their children. So you would hope that money at the end of the day isn't the deciding factor - and funding. So basically that's all I was here to say - talk about Emma, talk about her decision and what she wanted to do.

MRS OWENS: That's an excellent presentation, so thank you very much for that. You've probably given up more of your work time to come in here this afternoon. It's a very helpful presentation for us. We're getting a very clear idea and understanding of the issues facing independent schools from going around and we've had quite a lot of them put now from the independent schools sector. This whole issue of the funding arrangements is of concern. It's partly outside our terms of reference but it is an issue that we will be raising in our report because I think it is about providing everybody with the equivalent amount of opportunity in terms of being able to make other life choices later like when Emma wants to do architecture. She needs to get the proper education first and if she doesn't get that at this stage that's going to jeopardise that ambition. I think that's very, very unfair.

MS RICHARDSON: Yes, it would be a shame.

MRS OWENS: Because every other kid has got the opportunity to pursue whatever their goal is.

MS RICHARDSON: That's right.

MRS OWENS: Some fall by the wayside for various reasons but you don't want it to be this reason.

MS RICHARDSON: That's right, and that's what we instil in Emma, to focus on her abilities and not her disabilities, and that's what she does. You would hope that that would continue throughout her life. For that reason we try and make it as easy as possible. As I said, children with disabilities have enough hurdles in life. Every day is a bit of a hard day.

MS KERSTEN: So do their parents.

MS RICHARDSON: Yes.

MRS OWENS: It does raise a very important issue and that is the issue of who should pay. The choices are that the taxpayer, the community pays. The school community pays, that is through fees that are shared across the whole school community and they would be higher fees than they would otherwise be, or the individual parent pays. At the moment we've got a little bit - there's a mixture of all of those factors and I suppose it is, what should the right balance be? Should individual parents have to pay all these additional costs? Should it be the rest of the school community where it's spread over, and that becomes very unfair because you've got the small schools - in the case of Emma's school, that's quite a small school that's spread these additional costs over.

If she went to a larger independent school it would be less noticeable in the fees than it is in a small school, so it raises the fairness there or should it be the tax paid more generally when we're talking about giving people the same entitlements to an education or the same amount of choice as other kids have got. Not everybody can choose to send their child to an independent school, even if they wanted to, because there are fees. But when you set that aside you've already made a choice to pay fees, but should you have to then pay more?

MR ROSS: I guess what we're saying too is that amount of support, wherever it comes from, should be the same in a non-government school as it is in a government school and at the moment it's not.

MRS OWENS: That's right. The dollar should follow the student.

MR ROSS: Exactly right.

MS RICHARDSON: It should be tagged. I think every disabled child that maybe enters the mainstream school system, whether they go to an independent school or to a government school, that child should be tagged, "They are level 4 or they are level 5," and their funding should maybe follow them right through their schooling, whether they're reassessed at the end of primary school and reassessed through high school, but their disability isn't going to change. Emma didn't all of a sudden not have cerebral palsy when she went from a government school to a non-government school, she still has it.

MRS OWENS: That's right.

MS KERSTEN: I guess on that issue too of the funds - Emma transitioned at the end of grade 6 into grade 7 but, say, if she left at the end of term 1 of grade 6 her previous government school would have been allocated the 23,000 in the aid and none of it comes with her. So there's almost a double layer to that inequity of the funding that a number of kids - and you would be able to see too - that pop up in your school in the middle of the year that may have been funded at a government sector school, and their funding remains there but the child moves on.

MR ROSS: If the children come in during the year most of the AISV state funding is exhausted so that the child comes - - -

MS McKENZIE: Because it has all been pre-allocated.

MR ROSS: Exactly.

MS KERSTEN: It gets allocated at the beginning of the year.

MR ROSS: The $17 is allocated to those - - -

MS McKENZIE: Whoever there is at the beginning of the year.

MRS OWENS: So there's a real incentive, isn't there, on the part of the school to say, "No, we're not going to take anybody in the middle of the year."

MR ROSS: But it doesn't happen.

MRS OWENS: It does raise another question and that is if the school has already got a few children with a disabilities there and having to pay out all these additional costs or the parents have to bear these fees, then the next kid that comes along might miss out because there's already enough children to cope that it raises a dilemma for the school then. The parents can say, "You've already got another child with cerebral palsy there, why aren't you taking my child?"

MS KERSTEN: That happens a lot in the independent sector and particularly in schools that are doing a good job. It gets known in the community - your school was a fine example, it just grew unbelievably because the community in the area knew that Billanook catered well for all kids with disabilities and you would probably have the highest proportion percentagewise - what are you now, about 5 per cent?

MR ROSS: Yes, just on.

MS KERSTEN: 5 per cent. Current statistics of disabilities is 2 per cent of the population and he's got 5 per cent of his school community. Then you get to a point of saturation, "How much can our teachers accommodate these children well?" and when can you make a ceiling on that. Sometimes school principals will ask me, "If 2 per cent of my population has disabilities, therefore does that mean I don't have to enrol any more?" and I said, "Well, no, you could be in an area where the percentage is different," and according to the act, if you can support their needs, you should enrol them.

MR ROSS: We have government schools who refer children with special needs to us knowing that the funding will dry up as soon as they transfer and that's, in a sense, led to us being known as "a special school" to which I reply, "Yes, very special." But the funding doesn't come with the speciality.

MS KERSTEN: That's right.

MRS OWENS: You've raised this other recommendation or idea in here about a tax deduction for recurrent gifts towards the education of students with disabilities. Could you just give us a bit more on that. This was in your submission on page 16.

MS KERSTEN: I guess it was a move that would allow schools the opportunity to offer parents, grandparents and extended families and benefactors incentives for private recurrent investments in the education of the school-age children. It's currently enjoyed by universities but not by schools. But it was looking at the scenario of, "Well, we haven't got enough funds to support these children, let's look at a" - because some parents do put in $20,000 above their school fees so that their son or daughter can have the aid and they don't get any tax incentive for it. So until something is done at a government level about supporting the needs of these children - it was an alternative option that we looked at, that perhaps that would make it easier for families that were already doing that, and a number of grandparents and extended families are doing that for families of students with disabilities.

MRS OWENS: So it's really the second-best - you'd rather the government adequately fund it.

MS KERSTEN: Yes.

MRS OWENS: But if the government - - -

MS McKENZIE: It's the second-best option.

MS KERSTEN: Yes. This is currently happening, that sort of donation.

MS McKENZIE: Yes, it's just that it's not tax deductible.

MR ROSS: Not tax deductible.

MRS OWENS: Why limit it to recurrent expenditure, why not for any capital expenditure?

MR ROSS: A lot of schools have building funds or foundations, and for capital works contributions to those funds would be tax deductible. But there's no reason why it needed to be limited to recurrent. But the ongoing need in a school is really the recurrent funding. It's the people to support the individual student in his or her learning that is important and ongoing rather than a ramp or some of those physical things which are - - -

MRS OWENS: Once they're done, they're done.

MR ROSS: The schools are getting better whenever they build new buildings to ensure that - - -

MRS OWENS: Thanks to the Building Code.

MR ROSS: Yes, special things are required.

MS McKENZIE: Yes, they're accessible.

MRS OWENS: I think we've just about covered everything. I think we have really covered a lot of these issues with the other associations as well. We have had some terrific case studies. One of the submissions, I think it was the National Association, gave us the case studies of the financial impact of the education standards introduced, hypotheticals of what it would mean in terms of the additional cost of children with different types of disabilities and very extensive.

MS KERSTEN: Can I just comment on that. I had a look at it with New South Wales AIS and I guess our stance here - to me that's a Utopian sort of dream.

MRS OWENS: The standard?

MS KERSTEN: No, the scenarios that the National Council brought up of the costs associated. Like, if you could think of every possible wonderful service that a child requires - now, that's just not reality in today's world. What we've taken the basis of is we want our students to be supported like government students in this state. Whether or not that is the perfect scenario and the full funding and this service and that service, it's basically just getting to a level playing field for these students. So as much as I agree with what they've done and it's great to see on paper and, yes, it's a costly exercise, but I sort of have a tinge of, "Yes, that is in a perfect world and it's not a perfect world, let's be real." If the commission is going to make an impact on this, let's just be real about it and let's get equality for these children. I guess the next step is the equality, is it good enough. But I think they've just gone that step - - -

MRS OWENS: One step at a time.

MS KERSTEN: Yes.

MRS OWENS: I think it was quite an important point that they made, even if the dollars are at the Utopian end and that is that is if this standard was introduced it's going to be mean that more resources would be required - - -

MS KERSTEN: Exactly.

MRS OWENS: - - - and has anybody been giving any thought to those additional resources, far less where we are now with your dilemma as of now, what's it going to mean in the future.

MS McKENZIE: I think those case studies were based on, if you like, full compliance with the standard. The assumption was that everything that the standard said was going to be, was going to be done and to the extent that the standard required. So really I suppose what you're saying is that in a way the standard itself is almost a dream.

MS KERSTEN: That's the best case scenario. But I guess we should be aiming for that ultimately for students to have the best case scenario in their education. But, as I said, reality - let's just go one step at a time and just let's get them some equality.

MRS OWENS: But you would support the standards?

MS KERSTEN: Yes, only on the proviso that if you can meet them because they are the best case scenario.

MS McKENZIE: But the difficulty about that is you get the Rolls Royce standard with the defence of unjustifiable hardship which means that everyone who can't afford the Rolls Royce standard may well take the defence and you're going to have less enrolments.

MS KERSTEN: That's right, and I'd say there would be very few that could meet those standards.

MRS OWENS: I think that has been excellent. Thank you very much and I think we have probably gone on longer than we told you we were going to, so I apologise for that.

MS McKENZIE: Thank you very much for such an interesting submission.

MR ROSS: Thank you for the opportunity.

MS KERSTEN: Thanks.

MR ROSS: We really appreciate it.

MRS OWENS: Thank you especially to Emma for coming in. That concludes the formal part of our proceedings today. Is there anybody else that wants to say anything else on the transcript today or will I close. Thank you for attending today and we resume tomorrow morning at 9 am in this room.

AT 5.16 PM THE INQUIRY WAS ADJOURNED UNTIL
WEDNESDAY, 23 JULY 2003

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