TRANSCRIPT
OF PROCEEDINGS

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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 WEDNESDAY, 23 JULY 2003, AT 9.07 AM

Continued from 22/7/03 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 will refer to as the DDA. My name is Helen Owens and I'm the presiding commissioner on this inquiry, and my associate commissioner is Cate McKenzie. The hearing will have breaks for morning tea, lunch and afternoon tea, and we'll need to stick fairly closely to the timetable.

On 5 February this year the government asked the commission to review the DDA and the Disability Discrimination Regulations 1996. The terms of reference for the inquiry ask us to examine the social impacts of the DDA on people with disabilities and on the community as a whole. Among other things, the commission is required to assess the costs and benefits of the DDA and its effectiveness in achieving its objectives.

We've already talked informally to a range of organisations and individuals with an interest in these issues, and submissions have been coming into the inquiry following the release of the issues paper in March. The purpose of this hearing is to provide the opportunity for interested parties to discuss their submissions and their views on the public record. We've already held hearings in all other Australian capital cities, and are finalising hearings in Melbourne this week. We'll 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 these hearings in a reasonably informal manner, in spite of the microphones, 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. If anyone in the audience wants to speak, I'll be allowing time at the end of proceedings today. Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. You're 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 hearings.

I invite our first participant today, Blind Citizens Australia, to present to us. Could you each give your name and your position with Blind Citizens for the transcript?

MS DIAMOND: Maryanne Diamond, and I'm the executive officer of Blind Citizens Australia.

MS McFADZEAN: My name is Aileen McFadzean, and I'm the national advocacy officer at Blind Citizens Australia.

MRS OWENS: Thank you, and thank you for coming to see us so early on such a miserable morning. I'd like to thank you for your submission, which is a very complete submission. It covers a wide range of areas, and it also I think is very useful for us because you've had a lot of experience with the act and you've had experience with the complaints processes, standard setting and inquiries, so I think we could have very valuable discussions about this as we progress. But I'll hand over to you - I understand Maryanne wants to make a few opening remarks.

MS DIAMOND: Thanks, Helen. Blind Citizens Australia was pleased to have the opportunity to provide a submission for this inquiry and to meet with you today. I'll highlight issues raised in our submission which are not presented in any order of priority. People with disabilities have long argued that disability is a social problem, not a medical one. In terms of capacity to participate in society, actual medical impairment will rarely be important. What is important is the extent to which social infrastructure and community attitudes accommodate the impairment,

Blind Citizens Australia is pleased that the education standard under the DDA is finally proceeding, as it will highly benefit students with disabilities. We repeat our assumption that standards under the DDA are extremely important, making it more likely for change to occur in society at the time of developing programs and products. Using the complaints mechanism which sometimes may end up in the Federal Court is a real risk because of the potential for costs being awarded. Blind Citizens Australia would like to see the DDA amended so that organisations such as ours could lodge complaints.

We do not believe the definition of unjustifiable hardship requires further clarification. If the DDA were to be amended to include a positive obligation to provide reasonable adjustments, then the term would need to be defined, and should include adjustments which do not result in unjustifiable hardships. The cost of reasonable adjustments in the employment context are currently being met by the employer, by government subsidy or by the employee with a disability. We believe that discrimination in employment is rife, and that people with disabilities do not frequently request that adjustments be made, for the fear of not gaining employment, creating trouble in the workplace or being dismissed. This can of course affect the productivity of the worker and sometimes the business.

We believe that government subsidies for workplace modification should increase to make it easier for workers with disabilities to express how they need to perform their job. Pre-employment testing and occupational health and safety concerns can move people who are blind out of employment unnecessarily. The emerging trends in technology make it more difficult for people who are blind to gain and maintain work. We see that the public sector has a responsibility to increase the employment of people with disabilities, which has greatly decreased over recent years. Our experience is that the recruitment agencies are not putting people with disabilities forward for positions, therefore employers are not able to meet with and see for themselves the skills and abilities of people with disabilities.

Blind people who seek to migrate to Australia and who have business and professional skills that could be used productively in Australia are consistently refused entry on account of their blindness, notwithstanding that they meet all other eligibility criteria for the visa for which they are applying, and do and are able to give guarantees of financial independence. We believe that all persons satisfying criteria to enter Australia should be granted the appropriate visa, and the fact that they are blind should not be a factor. The current situation is based on a medical model which is most inappropriate.

Regarding issues surrounding the development of benchmarks for measuring the social inclusion or exclusion of people with disabilities: internally we are looking at identifying benchmarks of inclusion that are specific to people who are blind or vision impaired. Generally we are looking forward to working with the soon-to-be-established Federation of Disability Consumer Organisations to help develop cross-disability measures.

We note the commission's comments that there is little data available that can be used to assess the benefit of the introduction of the DDA. We have long been advocating for increased resources to be dedicated to researching the needs of people with disabilities and are hopeful that the current work of the commission may lead to additional resources being found for this area. As outlined in our submission, many blind and vision impaired people have encountered discrimination in obtaining life insurance and/or superannuation, which is generally based on no sound evidence. Our concern is that there are organisations claiming outcomes from research that we believe is based on particular agendas and outcomes sought, not independent studies.

We acknowledge that there have been some positive changes for people accessing jury service, such as here in Victoria, although our experience tells us that for blind people it is extremely difficult to be able to participate as a jury member. Access to information remains a significant area of discrimination for blind people. However, the DDA has had a strong impact in increasing public awareness and the compliance with requirements to make information accessible.

The successful outcome in a case Bruce Maguire brought against SOCOG has been seminal in improving the ability of blind people to access information in their preferred format. In particular the outcome of the web site complaint has created an emphasis for people to ensure that accessibility of their web site. Such an impetus would not have been possible without the Commonwealth DDA as a vehicle to assert the right to equality of access to information.

The DDA has had a significant positive effect on discrimination against people with disability in the administration of Commonwealth government laws and programs. Blind Citizens Australia has been able to effectively use the Commonwealth disability strategy to raise and resolve instances of discrimination in the administration of Commonwealth laws and programs, in particular, with reference to the provision of information to blind people in inappropriate and inaccessible formats. On other issues, in particular accessible voting and discrimination in migration, insurance and superannuation, there has been little progress, and we would suggest that one of the barriers in this progress in these areas is the breadth of the applicable exemptions under the DDA.

Implementation of the DDA and the Commonwealth disability strategy remains extremely patchy across the Commonwealth. Higher rates of employment of people with disabilities by government agencies is essential, and discrimination against people who are currently employed is still all too frequent. They are just some of the things that we highlighted out of our much more lengthy submission. I'm sure you have others that you might like to talk with us about.

MS McKENZIE: Thank you. It's a very helpful submission. Can I start perhaps by raising the issues you've raised about the definitions of discrimination, in particular the comparator problem.

MS McFADZEAN: You'd like us to speak on that?

MS McKENZIE: Yes, sure, I would like you to.

MS McFADZEAN: My experience in relation to some of the case work that we've done is that it's easier when you're perhaps talking about discrimination on the grounds of sex or race to compare what the situation would have been but for the fact of being a woman in some circumstances or a person of a different race or ethnic origin, but when you're actually talking about disability, it's very hard when some of the adjustments needed to be made in the workplace can effectively sometimes change the nature of the job that's being performed or the way in which it's performed.

Particularly if certain aspects of the duty statement are changed, it can mean that it's very difficult to compare the situation of a person with the disability with a nominal person without a disability, even when you take into account the adjustments that have been made in the workplace. Sometimes that still means that you can't compare what it would have been but for that situation. So we've sometimes struggled with that, not so much at the level of where you're pushing a matter at conciliation, but certainly when you're providing some legal advice as to how something might go in the Federal Court or the Federal Magistrates Court. It can be much more tricky. I think that's what you were alluding to?

MS McKENZIE: Yes, and that's what leads you to say perhaps that the comparator shouldn't be there at all. You just look at unfair treatment.

MS McFADZEAN: Unfair treatment. I guess what happens a bit, because we have had some cases - and certainly the Nerilee Humphries case was one example, which also connects back to our issue that there does need to be a positive obligation to provide reasonable adjustments. The fact that she really couldn't do her job without those adjustments or she couldn't really perform that job to the best of her ability and was at some disadvantage in that workplace was not sufficient because not only was it the issue of the comparator, but it was also part of that definition which is because of disability.

They said that she wasn't discriminated against because of her disability, and there was no positive obligation to provide those reasonable accommodations to her, as long as they weren't treating her less favourably, which means she was being paid at the same rate, she wasn't going to be sacked because she wasn't performing those other duties. She just had a much more limited employment experience. So the combination of those two things made it much more difficult for her to argue certainly direct discrimination.

MS McKENZIE: And the real problem is this inclusion of the reasonable accommodation mentioned in just the definitions of the circumstances for the purposes of the comparator. It's extremely difficult.

MS McFADZEAN: It's extremely difficult and, as I said, many more cases - I guess this has also been influenced by the more limited role now of HREOC in only handling matters to conciliation. I would say that respondents are more aware that it is more onerous for a complainant to take the matter on to the next level. It was relatively easy to take a matter on to the commission on an understanding, really, that no costs would be awarded unless your case was vexatious or frivolous, and it was much easier for community organisations such as ours, because of the more informal structure, to put more resources into really handling those cases to a certain level. You know, we're so heavily involved in the Maguire case and others, and one of the first ones to come out, the Amanda McNeil case against the Department of Social Security.

It was much easier for us to put - even though we couldn't, of course, fund the cases ourselves, but it would put enough pressure on respondents to take the matter more seriously, rather than just basically refuse an outcome at conciliation. So it certainly decreased our bargaining power. I'm sorry there, I've moved off from the issue of reasonable accommodation.

MS McKENZIE: No. It's a related subject. The other thing, I suppose, to say about that is, you say you want to be able to initiate complaints - you and other representative organisations?

MS McFADZEAN: Yes.

MS McKENZIE: But that surely - given what you've just said and what your submission is - would have to be coupled with some kind of no-costs jurisdiction.

MS McFADZEAN: Yes. Well, what we found was - and that's where we disagreed with what was in the Productivity Commission - we've found that most recently the information we have, just from some case reading and also speaking to other practitioners in the area, is that, really, the general costs rule will apply.

MS McKENZIE: I think there's no doubt that that's the case.

MRS OWENS: I think we've actually been hearing that from a lot of people.

MS McKENZIE: That's right. So it's not enough that - I mean, people say if it's a test case, but frankly, the actual jurisprudence in this area is - despite 10 years - is still extremely new. It's actually very easy, on issues of law, for something to satisfy the basic criteria of a test case. But that won't be enough. It would have to be extremely exceptional. That is why in some ways - it also led to our comments about the overlapping jurisdictions between the state and federal - is that in designated cases we would prefer to operate in the state jurisdiction.

MRS OWENS: So is that what you mean - this whole costs problem has made you treat DDA almost as a last resort, where you wouldn't have done that before?

MS McFADZEAN: Well, we are in probably a different - it is very multi-faceted. We're in a different position from a lot of organisations that are state-based, in the sense that I would represent people in all the different states and territories, and certainly the benefit of still using the DDA, despite the costs problem, is that HREOC as a national body is much better to accommodate, where you've got a lawyer in one state, a complainant in another state, the advocate in a third state, so their procedures for investigation and conciliation mean that you don't necessarily have to travel to a conciliation, where that's going to be - cost is a problem. Whereas of course, if you lodge for a complainant in a different state, their facilities for us in our advocacy work aren't as good.

MS McKENZIE: And also presumably where you've got complaints that, while they raise an individual problem, really raise a problem that is a national one. Maguire is really one of those cases.

MS McFADZEAN: Look, you're exactly right, Cate, that especially - a lot of our cases actually do end up being against the Commonwealth, particularly in relation to Commonwealth laws and programs, where we do think that the Commonwealth has an obligation to be - for best practice. So we do use the DDA in those situations, and we would hope - and it does actually bear out - that the Commonwealth of course, despite our ghastly experiences with the Humphries case - that the Commonwealth, in relation to process, the administration of a law and program, is much more likely to settle at conciliation.

When it comes to employment discrimination, we've found it to be a different kettle of fish, and it's a bit difficult for us to explain why. We've got a very interesting case going on at the moment, an employment discrimination case, and for us it's quite distressing to see that these aren't at times cases of just neglect, but there can be quite active, conscious, less favourable treatment of workers with disabilities still going on in the Commonwealth sector - things that really should not be happening at this time.

MS McKENZIE: The other difficulty you raise is concerning employment agencies, that they don't tend to put people with disabilities - in particular blind people - forward for employment, and that seems to me to raise what is a real problem area as far as employment agencies are concerned. I mean, the employment agency might well say, "Look, our clients say that these are their needs, and that's why we're not putting a person with a disability forward." You've got, in a way, a sort of double discrimination problem.

MS McFADZEAN: That's exactly right. We believe the problem is increasing as there is more outsourcing. It's quite interesting that one of those cases that we ran involving a recruitment agency was the first case that we really ran under the victimisation clause of the legislation, because we find that the recruitment agency probably would put a person forward. But what can happen is that they're not particularly skilled in presenting to the employer that they actually do have someone coming with a disability, but they're perfectly well skilled for the job.

So the person arrives, the recruitment agency doesn't have the knowledge or expertise or for whatever other reason hasn't actually done what we would hope would ordinarily happen in the employment context of making sure that the person works with the appropriate adjustments to enable them to perform at the same level, so they go in cold to an employment, to a company, and often it's corporate, and where unfortunately image tends to be extremely important, and it can be as mild a thing - or as small a thing as someone looking too closely at a screen, which raises for the employer notions of incompetence.

Then they send the person back, usually with a threat that, "Look, if you send somebody like that again, you lose our contract, we'll go to another recruitment agency," and then that person is on the books. The recruitment agency apologises to the person with the disability and says, "Look, we just can't put you forward," or they just leave them dangling there for quite a period of time.

MS DIAMOND: There's other issues too, of course, with high unemployment. You know, the recruitment agency has got a number of people who are quite skilled for the position, and it's easier to put everyone else forward; we understand that. Also the other factor too is, the workplace modification program, which is administered by government to provide the adjustments for the workplace, often takes so long to kick in or to even get the assessment, and we know this from our own personal experience - that if it's a short-term contract, and lots of jobs are these days, the term is nearly over before the modifications are even paid for, so the person with the disability sits around doing nothing and then of course the employer does see them as incapable.

MS McKENZIE: Can you talk to us a bit more about that. We've certainly heard that there's a problem - that a lot of employers, and perhaps even recruitment agencies, aren't aware that these programs exist, but we hadn't yet heard that there are difficulties about delay in actually doing the modifications.

MS DIAMOND: Well, our experience is that people don't know about them either - that is, individuals who could access them, often don't know about them, employers don't, and I think the program is accessed by very few people. Even some of the job network groups themselves don't even access the program. What happens is, you need to have an assessment done - you know, a person with a disability has an employment agency person come in, or a specialist person come in, do an assessment - it could be an OT, it could be a specialist in blindness - it might not be an OT, it might be someone who knows about adaptive equipment - come in and do an assessment of the workplace, and they write a report identifying the requirements.

That report goes in to FACS and then you wait for an outcome on yes, no, "You get the money" or, "You don't get the money." Then of course there's delay while you buy it. Small businesses - and BCA is one of them - can't always afford to put the money up-front, unless we've got a guarantee we're going to get it reimbursed or - you know, in some cases we would have to wait for the money to come through.

I know of many instances where people - and blind people - have been offered three-month contracts and in that three months they've got no equipment. Even ourselves, I tried to look at accessing the program for one of my own staff members, who isn't blind but has another disability, and I found even talking to the work modification people, they all told me different information as to who I needed to go and access the program through - like, you can't go direct to them, you go through an employment agency or CRS or Royal Victorian Institute for the Blind, for example. I got different messages as to where I could go, and even when I spoke to each of them, some of them said they didn't even know anything about the program. I reported that back to FACS, but it's a bit of a problem.

MS McFADZEAN: So even the couple of employment agencies who are there to assist people with disabilities into employment, were not aware of the workplace modification scheme. Certainly there's a gap between giving assistance to workers commencing employment - as difficult as it might be - and the workers in employment, because to access a scheme that will assist the employer to pay for modifications, you either have to register with an employment agency, who won't want to register you because you already have a job, and then you get referred to CRS, who won't be able to fund you to the same extent as the Workplace Modifications Scheme.

So workers in that situation are in the difficult situation of whether they push for modifications, and not only to perform their current job, but the difficulty of workers with disabilities to actually go for a promotion or some kind of movement - it seems to be that once the equipment is got which will assist with the current position, that seems to be where people remain, because then they would have to ask perhaps for training materials or more equipment to move up to these levels.

MS DIAMOND: But also, the equipment may break down.

MS McKENZIE: And they have to go through the same round again?

MS DIAMOND: Yes. But also the equipment often - and as you would know - needs maintenance, repairs, upgrades, and that's often difficult too. We've got people who might have, say, Jaws - which is the speech program for computers - sitting in employment maybe, but on a version that's so old, but now is not compatible with the computer software used in their business. So unless they go through the whole program again - and they're not likely to give you the same thing twice.

MS McFADZEAN: Do you mind if I mention something that has come to my mind that we should have mentioned in our submission?

MS McKENZIE: Please do.

MS McFADZEAN: Sorry, we're going to talk your heads off.

MS McKENZIE: It's okay, my head is still there. So is Helen's.

MRS OWENS: I want to actually go back and revisit a few things too.

MS McKENZIE: We will.

MS McFADZEAN: Yes, sure, but I'll do this while it's in mind. One area in which the legislation works very badly is for when you're trying to demonstrate that a worker who has gone for a job interview and has not got the job, that discrimination has occurred. It's much easier to show that discrimination has occurred when a worker is in employment, because demonstrating that the worker with a disability was the best person for the job, is extremely difficult.

I mean, in many cases the differences between workers are very marginal, and the employment of one person over another can be based on things other than necessarily what's on the resume. So we find, of course, in running a discrimination case, that access to details about other job applicants is very very difficult to get, and very difficult to prove. Even though you know that that's probably what has gone on, the sheer fact that that person is going to be - and it's not recognised in the discrimination law, and it's not recognised really by society - that in many ways employing a person with a disability is harder, is more difficult. It's assumed that every - and disability advocates fall into this trap and say, "Look, a worker with a disability is as good as and can do just as well as another worker with a disability."

Now, in a perfect environment, that will be. But of course, in a situation where an employer is faced with someone walking into a room, who is completely blind or obviously partially sighted, their fear reactions occur, they think, "Oh, my God, this is going to be slightly more hard - this is going to be harder for us," and therefore the person doesn't get the job. Of course, those cases are very difficult to run for us.

MRS OWENS: There's a high level of subjectivity in the employment process, and even if the employer has a set of criteria laid down, there's still subjectivity in how you apply those criteria, how you weight the skills of different people, and I think it's going to always be difficult. But you said it's not quite so difficult once the person is in the job, but I think it also could be a problem there as well; maybe not as great.

MS McFADZEAN: Look, it is. So we're constantly asked by workers, "What do I say?" I don't want to roll up and frighten, you know, the socks off them." We find that if a person puts that they are blind or they have a disability, in a job application, they won't get an interview. So they actually have to go - and if they are partially sighted they will generally - and I hate to say it - fudge their way through that aspect; won't mention it in the interview. And we generally would recommend, despite every other part of me that sort of rebels against needing to do this, that when the job offer has been made to raise the issue of adjustments then because it's only then that you really stand a chance that the commitment will be carried out.

MS McKENZIE: People with mental health issues have made a very similar submission to us. And the other thing that a number of people have said in their submissions is that an employer, who is aware of the discrimination legislation, that actually wants to discriminate - if disability is a factor - will simply give another reason for it, and there are hosts of other reasons that can be given and are very difficult to challenge.

MS McFADZEAN: Yes.

MRS OWENS: Exactly. But another problem of waiting till the job offer is that sometimes the applicants are required to fill out a form earlier, which then asks questions like "Have you had a workplace injury? Have you been under workers compensation? Have you got anything we need to know about?"

MS McFADZEAN: In which case we've always advised them to be completely truthful, which is a problem, as we point out in our submission, with the greater amount of pre-employment testing that is around. Yes, it is more difficult.

MRS OWENS: Can I just go back two steps, maybe three? You talked about all the cases against the Commonwealth - a lot of the cases you deal with - and one of the issues that has arisen is this imbalance, in terms of the legal advice that people with disabilities can get versus what the Commonwealth can bring to bear in a case, particularly if it goes through to the Federal Court or the Federal Magistrates Court, because the Commonwealth, at the end of the day, can wheel in the solicitor - the Commonwealth solicitor and so on.

MS McKENZIE: And even in conciliation.

MRS OWENS: And even in conciliation that can happen. Has that been something that struck you?

MS McFADZEAN: Certainly - and I make no bones about it - in relation to the Humphries case. We'd have to estimate that the Commonwealth, in that case, must have spent close to 500,000 defending that case. We originally - and I won't specify it because it was confidential - to settle that case, I'd have to tell you, for under $10,000. It was inexplicable to us that that was able to proceed. I think once the Commonwealth sort of got involved with the Australian government solicitors it just developed a life of its own and went off.

MS DIAMOND: But it's not just the Commonwealth who can do that. We've had other situations where - you know, we've got Aileen, who works three days a week as our part-time advocacy officer and we are very lucky that she is, by training, a lawyer. That's not the case in a lot of disability organisations. But even so, there are almost no resources except for the three days a week. And we've had cases where, even in the conciliation stage, other parties are putting up Queens Counsel, you know, a whole line of lawyers. And here's Aileen sitting kind of on the other end of the telephone. I just think it's an unfair system. Well, it's not equal anyway.

MS McKENZIE: Can I ask? When you say "the telephone" - - -

MS DIAMOND: Sometimes phone, sometimes in person.

MS McKENZIE: We've had at least one submission where the people who had a telephone conciliation found it difficult and would have preferred a face-to-face one. How many telephone conciliations does HREOC conduct?

MS McFADZEAN: Probably quite a lot. Certainly, when there's an interstate matter it is almost inevitable that it's going to be that way. When we had more resources the way we looked at it in terms of cost saving was where a matter was more or less - it was strategic and it was important to the person, but it was largely personal. Say, for example, you are talking about the inaccessibility of a web site, then that is a matter that can be reasonably appropriately dealt with over the telephone. If, for example though, you've got a workplace situation where you've got the employer and the employee of course sitting in the same room and their advocate over in Melbourne, then of course that puts the person at a tremendous disadvantage. So if it's personal, in terms of employment or education or someone being tossed out of the sporting club or something like that, then of course it is disadvantageous to have it over the phone. However, if it is a more arm's-length kind of matter - - -

MS McKENZIE: Yes, then it's easier.

MS McFADZEAN: Then it really doesn't - - -

MS DIAMOND: Like a product rather than a person.

MS McFADZEAN: That's right.

MS McKENZIE: Yes.

MRS OWENS: Can I go back three steps, now? When we were talking about comparators - sorry, we are going right back - and you talked about instead of having a comparator, having some reference to unfair treatment.

MS McFADZEAN: Mm.

MRS OWENS: I'm struggling with this; I'm not a lawyer. So I wonder how you define "unfair" and whether implicit in the word "unfair" is some sort of comparison with something else.

MS McFADZEAN: Where that sort of came from was when I was doing a lot more international jurisprudence studies, and I may be quite wrong because it has been some time since I've done this, but certainly when I compared it to the approach that was, say, taken in Canada a while ago, they had moved away from that. This person has to be compared to that person in the same circumstance when clearly some of the disability is not going to be in the same circumstance. Say, for example, if I think back to a couple of the employment cases that I've got now, there is always going to be, to the reasonable person, a test. There is always going to have to be some kind of objective measure. But I would say that on the face of it those cases - you could see that the person had received unfair treatment.

MRS OWENS: But what's unfair compared with what - - -

MS McKENZIE: No, it's just that basically what the law says about words like "unjust" or "unfair" is that they apply a much broader test. What lawyers say, when they are faced with those words, is that they look at general concepts of justice and fairness rather than some very narrow comparison. So it doesn't look at unfair, as distinct from the way some fictional person in the community is treated, it looks at "What are the general notions of the community about fairness? And irrespective of your disability, if anyone was treated in that way would the community regard that as unfair?" And that's an entirely different approach from less favourable as compared with some specific notional person in the same circumstances. So it's a much broader test.

MRS OWENS: I find it quite difficult. Again, I'm not a lawyer, but what a person, say, in the workplace, may think of as being unfair may not be interpreted in law as being unfair in terms of community norms. Somebody might think that they've had very bad treatment but in fact it may not be. I just don't - - -

MS McFADZEAN: It would still need to be based on disability. Our problem is also, at the moment, that because of disability it means that - I think even though the legislation refers to the fact that discrimination doesn't have to be conscious to be discriminatory. The way direct discrimination is currently being interpreted, I think, in the Federal Court, is that it is almost requiring a consciousness of action. So just because someone's failure - some of the cases, if you are looking at - say you've got a worker who needs a monocular, which is like a sort of magnifier held close to the eye, or they need something else that is particular to that person's employment, like a closed-circuit TV or a magnifier - sorry, I'm going to lose track of what I was saying - that it's not enough that that person, in current law, needs those things because of the disability; it means that the disadvantage they have experienced has to be because of the disability.

I know that sounds like I have contradicted myself but it almost is requiring that that person has been denied those things because a person has a problem with their disability. It's not enough that the need for that adjustment is springing from that disability. The legislation, jurisprudence, at the moment seems to me to be requiring something more. Now, I'm hoping that that's going to be in some ways - if it went to the High Court - that that in fact won't necessarily be upheld in a future case. But it's currently - - -

MRS OWENS: I think that's a trend. I think you are quite right.

MS McFADZEAN: It is a trend, but the problem with the comparator is that it's all right if you are comparing a person - say, for example, you've got a vision-impaired worker who needs an anti-glare screen. Now, if that person is denied an anti-glare screen, but the sighted worker beside them gets an anti-glare screen, direct discrimination, as it's in the legislation, works very well; that person has been denied an anti-glare screen because of their disability. If that person needs that monocular and that closed-circuit TV, clearly stuff that in a pink fit the sighted worker is not going to require, can you say that that person has been denied those things because of their disability? Well, under the current law, no, they haven't. They are just choosing not to spend money - their budget - on those things.

MRS OWENS: On these extras.

MS McFADZEAN: On those extras.

MS McKENZIE: See, what the current law would say is that that's not unfavourable treatment; it's actually not giving them better treatment than other people.

MS McFADZEAN: That's right.

MS McKENZIE: That's how the current law works. But to return to your question of unfairness, Helen, if you look for a minute at the industrial relations jurisdiction, no-one has had any problem with saying whether or not a dismissal was harsh, unjust or unfair, and they look objectively - and yes, maybe in some cases what I subjectively think is unfair might not turn out, from the court's point of view, to be objectively unfair. But there has been no difficulty with much broader concepts. The real problem is that the concept of unfavourable treatment, coupled with the comparator, is a very narrow concept.

MS McFADZEAN: And jurisprudence has developed in unfair, unjust and unreasonable.

MS McKENZIE: Yes.

MS McFADZEAN: And we know, for example, failing to give three decent warnings on the error for which the person is dismissed is generally found to be unfair, unjust and unreasonable, but in practice it ends up not being as difficult as it would first appear.

MS McKENZIE: It is not an uncommon term nor is it one that there has been a real difficulty about.

MS DIAMOND: I think it's important - and Helen makes a point; and I'm not a lawyer either - that being confused about and what might be the case in law and what might be interpreted in the workplace, educational institute or whatever, is sometimes different to the law. So certainly my experience would tell me, in education, this comparison thing is a really big problem. It often doesn't get to the DDA or any complaints system because people don't lodge complaints because they are very clearly of the view that, "My child with a disability can't be compared exactly to another child because they are individuals." The disability is part of the make-up of this child. And so people don't even proceed, for lots of other reasons like they don't want to have their child less favourably treated in school and all that kind of stuff.

But certainly in Victoria, in the Victorian Certificate of Education, I do know - and this is first hand - that when students do year 12, who have a disability, they can apply and they are able to apply for consideration of disadvantage, just like anyone who breaks their arm or whatever, and what the school has got to do is state what they think that child would have obtained a score of if they didn't have a disability. Now, that's extremely difficult to do. If someone falls over the week before the exams and breaks their arm and also claims consideration of disadvantage that's not so hard to make an estimation of. We talk about employment a lot, it is a big issue, but I think education is equally an issue and, I think, a really big one and it doesn't hit the DDA, it doesn't hit any of them, so I'm hoping that the education standard might help this progress a little.

MS McFADZEAN: I think what Maryanne says is crucial because what we find is that students get very poor service, but it's very hard to measure, as Maryanne says, what the disadvantage has been. So currently, especially with the movement towards NILS, which is the sort of national producer of alternate format materials, has gone from only charging 8 per cent costs to tertiary institutions, and of course has gone to full cost recovery. So we find now that students who require braille just don't get braille now. So a student who has materials that are tactile - diagrams and things like that - are being pushed towards an audio medium which is not their primary literacy mechanism and so they won't get braille.

MS McKENZIE: It means they don't have a choice, in effect.

MS DIAMOND: They don't have a choice. Yes.

MS McKENZIE: Some people with vision impairments choose speech and some choose braille, and some like to do both, which is my case.

MS DIAMOND: But what I'm finding, the trend is that the university chooses because of budgetary reasons.

MS McKENZIE: Yes, the choice is made for them.

MRS OWENS: Coming back to NILS we will be talking to NILS either tomorrow or the next day - I can't remember which day. The issue of full cost recovery is an interesting one because the commission - we worked on an inquiry into cost recovery a year or so ago and set up some guidelines which have been adopted by government, and I'll ask NILS whether they are actually applying our cost-recovery guidelines.

MS McFADZEAN: That would be interesting. I mean - - -

MRS OWENS: I'm not sure whether a full cost recovery would comply with the guidelines.

MS McFADZEAN: We also believe, though, that provision of materials in an appropriate format to students should not be charity. We think that for children to really be in the same sort of situation as another child, that does require significant funding and it should not be left to blindness agencies, to come out of the charity dollar. But I certainly take your point on that other issue, and would be interested in that as well.

MS DIAMOND: But also, when we talk about full cost recovery, what makes it very difficult to determine is that when we say, "Well, how much does it cost to produce a page of braille?", you know, it seems to me that there's as many answers as people you might ask.

MRS OWENS: Or a piece of string, yes.

MS DIAMOND: And that, I think, is very confusing.

MS McFADZEAN: And the problem, we find, is that the competition principle doesn't work very effectively, so the Commonwealth might decide that the person that they're going to obtain information from is a particular producer but despite the fact that in circumstances we've given the details of other producers, they don't actually bargain for the best price. They just go with the producer that we would actually say, "My word, that is extraordinarily high. We actually think it's for profit, let alone cost recovery," and even then we'll be staggered that there is no movement towards contracting with a less expensive producer.

MS McKENZIE: Perhaps I should just say that - and I mean, I don't have information on this, but certainly in a number of the submissions figures have been quoted to use for vision-impaired students who required braille materials and the figures seem to be very high. I mean, it may well be that production costs are simply very high, but they seem to me to be amazingly high.

MS DIAMOND: I think they're higher in the bigger organisations, which is interesting. Our experience would say the small operator, small business who may produce braille is most often the cheapest option but it's least often called upon, as Aileen said, by government. We give them the name. We give everybody all names. We don't just say, "Here's NILS." We say, "Here's a range of people. We suggest you talk to all of them," recognising that there are some instances where the small business may not be able to provide the very specialist maths code or music code or something like that.

MS McFADZEAN: But we're finding sometimes now with NILS that they have problems producing those kinds of things but there is certainly one producer that we would recommend that probably could manage some of those skills but they don't tend to go for that producer. We also think that lots of the producers prefer the corporate work for which, frankly, they can build in a profit margin. They really don't want to do the work for students, so many of the universities are now doing their - they've got this poor, struggling DLU who actually is basically managing alternate format production. We do believe at this stage that, say, the University of Melbourne does a reasonable job. They've got an in-house braille production arm.

MS McKENZIE: Because it became so expensive to - trade rates, also.

MS McFADZEAN: That's right, and they had some decent DDA complaints lodged against them.

MS DIAMOND: And also at Melbourne University, what they did is they sought to undertake commitments by departmental staff - you know, texts, naming of texts and provision of material even in the printed form for production had to be given in a reasonable time frame, rather than the date the course starts, which happens in most places.

MS McFADZEAN: And we try to build that into conciliated outcomes which isn't the kind of thing that you'd go for if you're going to the Federal Court but actually established for universities and assist, work with them to develop those benchmark standards for information production. So you don't have lecturers producing tutorial notes on third-rate copies of something which then somebody else has to try to read off a scanner. But some of the universities despite on the one hand telling us that frankly they were so bureaucratic that it was very difficult for one department to work with this faculty and whatever that they would benefit from, in fact, something like a discrimination complaint.

The University of Melbourne was the only university that's prepared to take that really broad structural change, get all parties together and work on a policy for alternate format production. So we've found it very difficult to assist the universities, you know, who would have been able to say, "Look, we're being forced to do this by the DDA." They're actually curiously resistant. Sometimes we find that the departments and the faculties are far easier to work with than the DLUs. The individual lecturers would go out a long way for a particular student and yet the support coming from the actual so-called unit for students with disabilities is quite dysfunctional and aggressive.

MS DIAMOND: But in fairness, last year HREOC held a forum to discuss this issue, access to information for tertiary students, where most universities were represented and students were there and people like ourselves. A steering committee was established which we sit on and there's a number of working groups or committees under that. One of them is university procedures and practices and that's chaired by the Australian Vice-Chancellors' Committee and I am on that committee. We are really trying to push the universities into coming up with some common, even guidelines as to how they operate and communicate. That work is supposed to finish late this year. As to where it will end up, who knows? But instead of using the - you know, sitting alongside the DDA I guess we're saying that we're doing this work following that, I suppose - - -

MRS OWENS: That's like cooperative discussion, basically.

MS DIAMOND: Yes.

MRS OWENS: That sounds like a reasonable approach. It will be interesting to follow that up later in the year and you can tell us whether it's had a reasonable outcome.

MS DIAMOND: We've found the DDA is a vehicle but so are other things. I guess you would have read how - well, the banking stuff was one, where what we did - we sat down and strategically decided that we would work with the Australian Bankers Association. We were very lucky that we were asked for a representative on their working group, to develop the voluntary standards. But at the same time we did lodge complaints against all the banks, because we thought that would help the standards - - -

MRS OWENS: Strategically.

MS DIAMOND: - - - progress very quickly.

MRS OWENS: It worked.

MS DIAMOND: It did. We were quite open and frank about it. We told the banks that this is what we were doing and we were about to lodge a complaint against them. I think it did - wouldn't you say, Aileen? It certainly moved those standards.

MS McFADZEAN: It certainly did. But of course it also raises another interesting point that's in the Productivity Commission about once those standards are there. Now we've got these standards - our complaints were pushing the development of these standards. Now, really, I think that the implementation of those standards has gone somewhat cold, and that's very disappointing.

MRS OWENS: So then you really need some mechanism to both monitor and ensure that those standards are being upheld.

MS McFADZEAN: And in those circumstances, it's very difficult to run a DDA complaint, because this is what used to happen to us always when we were working with the, say, State Rail Authority of New South Wales. They'd tell us that they totally agreed with us, that, yes, those things should be there, it's their policy. They just can't make their individual staff do it. Therefore you're completely hamstrung. You can't actually win a case on that basis. But here were the banks, "Oh, yes, we're working towards it. We've got these wonderful standards. This is our time frame. It might take us till" - you know - "2050 to basically do it," and then, are you really able to lodge a complaint in those circumstances? It's very difficult.

MRS OWENS: I suppose having a voluntary standard is better than no standard.

MS McFADZEAN: Yes.

MRS OWENS: But then the question is whether it would have been better to have had a standard standard under the DDA? But that might have taken another 10 years to produce.

MS DIAMOND: Well, that's right.

MRS OWENS: So there's trade-offs here.

MS DIAMOND: This was the frustration. And when the voluntary standards were launched, there was a general agreement that, you know, they would be monitored and at one year later reviewed. That one year has passed now and we hardly hear from them; don't answer any calls.

MS McKENZIE: So there needed really to have been some kind of monitoring mechanism built into the agreement.

MS DIAMOND: Yes.

MRS OWENS: But you said there was one built in but they're just not doing it?

MS DIAMOND: I think it was a general agreement rather than built in.

MS McKENZIE: Not a specific monitoring mechanism.

MS DIAMOND: I mean, they can have lots of handshake agreements. They're easy. Like Aileen says, they all agree with you.

MRS OWENS: I was going to ask you about a similar sort of area. You talked about superannuation and insurance and recommended that section 46 in the act, the reference to "other reasonable factors" be removed. Some people have actually argued that the whole section should go, I should say. But there have been interesting models in that area. There's one where the Mental Health Council set up an MOU with IFSA, which is the Investment and Financial Superannuation Association, which is again - it's like a voluntary approach to dealing with the issue of insurance. Have you thought about trying to do anything like that in that area?

MS McFADZEAN: HREOC tried. I remember, I think it was two babies ago, being at a - - -

MRS OWENS: That's an interesting way of measuring time.

MS McFADZEAN: I always think, was it in between babies? Before first baby? After?

MS McKENZIE: That's a really good way of measuring time.

MS McFADZEAN: I know. But actually, HREOC had a project. It was a superannuation insurance committee and I was on that committee too and it just died. There was lots of general talk but as soon as it got to the point of actually saying, "What is your data? Oh, we'd love to do it, but we haven't got any data" "Well, what are you going to do to get some data?" "Oh, well, nothing." And HREOC was unable to take that any further or didn't take it any further.

MRS OWENS: Did you go through HREOC with the banks or did you just - you did your own thing there, didn't you, with the banking?

MS McFADZEAN: We lodged - it could even have been as a reaction to some of the cases we lodged in insurance. Admittedly, we tend to focus on particular areas and we haven't done much in insurance in the last couple of years; but, yes, it's sort of gone a bit cold. But, yes, we could lodge more complaints against insurers and we do give quite a lot of advice in relation to that.

MS DIAMOND: And sometimes just because we haven't lodged complaints in the last couple of years doesn't mean they don't exist. It means that the people knocking on our doors with problems aren't necessarily those people at this time - - -

MS McKENZIE: Yes. You must respond to your immediate problem.

MS DIAMOND: Yes. But one of the concerns I really have in that is, there are organisations around who are - and I believe for reasons looking at, say in the case of blindness - looking at raising money to research into prevention of blindness, are coming up and producing statistics that are saying, you know, "Blind people are twice as likely to fall over." Now, insurance companies get hold of that information and that's dangerous. I would say that their samples are usually done on, you know, very old people. You know, like skewed samples. I suppose one of the concerns I have, without any real independent actuarial information, you know, data, that this information will be picked up and maybe used across the board say for all people with disabilities, which is a concern.

MS McFADZEAN: So we've also worked in the area of trying to get things perhaps built into the census process. You know, having appropriate questions asked. That is a good opportunity to - sort of field research. But it is a difficult area. There has been research done overseas and we used to do - which is it, the institution in England, Maryanne, the main agency?

MS DIAMOND: RNIB.

MS McFADZEAN: RNIB has done quite a lot of work and we used to use their material quite a lot to support our cases. Actually we found a really fantastic actuary for one of our cases, who was actually - we went to the next level. It was actually the (indistinct) commission hearings, and he was able to completely undermine them. So that was really successful. Unfortunately, if you don't have an actuary on side, and one who's not going to charge you thousands to appear in court for you, it's very difficult to win. You're going to settle.

We used to try to just develop reasonable exclusion clauses. We weren't opposed to having - of course, they would say "Yes, but if we don't have any kind of exclusion clause, you can claim immediately because of your current condition." We would say, "Of course the current condition might need to be excluded if you're talking about income protection insurance, but you can actually develop a clause that works for both parties. But there is slackness. They just think it's easier to exclude rather than actually come up with a clause that is appropriate in the circumstances.

We find for things like income protection insurance and of course mortgage protection insurance, it is possible to develop a clause; but it's far harder to do that for the insurance company. They're not prepared to do that. They just exclude the person outright.

MRS OWENS: We asked IFSA the other day about this "other reasonable factors" clause in section 46, because it is a bit of a catch-all. It's a bit of a let-out clause and I suggested they might go away and think about could that be pinned down better? I mean, most people would accept that the whole basis of insurance is about risk rating and so on.

MS DIAMOND: Of course.

MRS OWENS: So to exclude on actuarial statistical grounds, okay, providing that's transparent - - -

MS McKENZIE: Providing the information is up-to-date and transparent.

MRS OWENS: - - - and so on, so that has to be something that's agreed on. Whoever the complainant is needs to know what that information was, be able to get access to it and it should be, you know, proper guidelines that have been set out and not just one company's guidelines. Then the question is, after that, "Can you pin down the rest?" Once you go past that, they talk about general research and so on. What is that research? Whose research is it? So if they're not going to have "other reasonable factors", it can either be replaced with another clause or don't have a let-out. So we're interested in this topic, because other people are raising it with us.

We've got the breast cancer people coming on Friday, but we've also spoken to quite a few others that have had concerns.

MS DIAMOND: You've also got at the moment the increase in the public liability insurance issue affecting blind and vision-impaired people's opportunities to participate in activities. So we find that we've had a couple of examples recently of blind people being refused to travel on a tour, because of so-called increased risks of accident and various other activities, where they've been refused outright the opportunity to participate.

MRS OWENS: I think that's being addressed just at the moment, isn't it, between the Commonwealth and the states?

MS DIAMOND: Yes, it is.

MRS OWENS: There's a capping arrangement being developed. We're just checking to see - - -

MS McKENZIE: I've just got to make sure that I've asked you all the questions that - it was a very good submission and there were numbers of matters that you - - -

MS DIAMOND: I guess if there's anything else that you do want to ask us, you can always call us.

MS McKENZIE: But we can't get that on the transcript.

MS DIAMOND: That's true.

MS McFADZEAN: The other thing I really want to give a plug to is the migration exemption.

MRS OWENS: Okay, tell me about migration.

MS McFADZEAN: It is of course on humanitarian grounds, I have to be frank. It distresses me greatly to see that people for no other reason except a disability will not come into the country. Even if say an Australian citizen marries someone overseas who is blind or vision-impaired, that person is 99 per cent likely to be refused entry into Australia. That is often despite the person having a range of skills, a decent job history - we've even found, been offered a job in Australia. We find that exemption is way too broad and it just means that based on disability there doesn't have to be any other rationale. What is decided by the Commonwealth that near-eligibility, even if it's eligibility in 10 years' time, for a service is enough to mean that a person doesn't get entry regardless of whether there is any likelihood that a person is going to utilise those services.

MS DIAMOND: I think the basic thing is that it goes to the medical tables or the medical assessment, so irrespective of anything that's written on the application form - once that medical assessment model is kind of applied, the person is dismissed straightaway, without taking into account any of their participation, their ability to contribute and so on, and their productivity. It's all irrelevant from - my understanding is that here we apply a medical model: "You fail because you're blind." "Yeah, sorry."

MS McKENZIE: An individual's circumstances, as far as you understand it, are not taken into account. Is that - - -

MS McFADZEAN: I can guarantee you that they're not taken into account.

MS DIAMOND: We have spoken to the minister personally.

MS McFADZEAN: He says they are not relevant. It is mere theoretical eligibility. So we once had a situation where a gentleman had skills in IT that meant that he would have been head-hunted, we would believe, by any company in Australia. He was denied entry into Australia and despite being - which also offends me on one level - extremely wealthy, he could not come into the country. We also have situations where we might have elderly people who are in good health who in any other circumstance would classify for the visa for aged parents to come and live with children.

The sheer fact that they are 70, they are totally blind or about to be totally blind, are in an environment that means they aren't going to be out getting employment services, they're not going to be out getting, you know, O and M training. They're in that situation where, you know, they went blind years ago. It is nonetheless those - people in that situation are just 100 per cent of the time rejected.

MS DIAMOND: And also instances of children, too. We have had cases of children who have been denied and in some cases where - - -

MS McFADZEAN: Children have run away from their parents, rather than be the factor that means that their parents can't come to the country. We find that very tragic.

MRS OWENS: I was going to ask you about your recommendation on this one. You talk about section 52 of the DDA, which relates to the Migration Act 1958, being amended. Some people have said it should go altogether.

MS McFADZEAN: Well, we think it will; but I frankly, in our continual - where we have been successful in arguing these cases is because we've been very sly. We've worked out what electorate they're in, what side of the house the person lives in - of parliament of course - and we've used indirect routes to get someone into the country. We find that the Australian health service is rigorous in its attitude. They've also got a lot more clever. It used to be that they used to provide reasons that were so easily disputable. They used to say that the person would be using this service, that a relative would be eligible for carer pension, all those sorts of things. So we were able to go in and say, "Rubbish, rubbish, rubbish, rubbish, rubbish." Decision overturned. Now they just say they're likely, they will be eligible for community resources.

MRS OWENS: But why are you arguing for the clause to be amended rather than abolished? Do you need a clause at all?

MS McFADZEAN: I guess in some ways that was a bit weak of us. We could have argued for it to be abolished and we would want it to be abolished; but in practical terms we believe that it's not just this government, it's been previous governments - they will want some control over - - -

MRS OWENS: Who comes in.

MS McFADZEAN: - - - who comes in and the cost. So we were thinking where - see, it would even assist people in - what we're arguing is if they would otherwise meet - in some ways we meet it anyway; if they would other wise meet, but for disability, okay, the qualification for that visa, disability should not be the factor. That would assist the couple of applicants I've got at the moment who live in Egypt who are about 70 years old. It would also have assisted with the child from - you know, who was Kurdish. They would come in. All the people we assist would be supported by the amendment that we've suggested. In some ways it's just a kind of more placating way of writing it.

We've even had a situation where it was very similar - you will remember with the fee, the father who set himself alight. We had a situation where a man was Kurdish and he had qualified - he was refugee, and he had two children still in Iraq. It was decided that because of the boys' very minimal impairments - of course, they were tested in - they don't speak English and they were tested in English, so their medical examinations were completely wrong, which is ultimately why they got in; but the situation was, they couldn't come to Australia because of the boys. The father couldn't go back to Iraq because he was a refugee. So that was going to be a situation where that family was permanently divided and the father would have risked death to go back.

MS DIAMOND: We did speak to the minister on that issue and basically the line was that because they're children they would be eligible for a number of services throughout their lifetime which would cost a lot of money with no guarantee that they would ever be productive, because they're children.

MS McFADZEAN: Ultimately in that case what eventuated was that the medical reports were completely exaggerated. They actually had very minimal vision impairment, so it was much easier for Minister Ruddock to make an exception in those circumstances.

MS McKENZIE: I suppose the concern is, if their visual impairment had been greater, all the other circumstances would still have been the same.

MS McFADZEAN: Exactly.

MS McKENZIE: The only other question I was going to ask you, and this is not related to any of the other questions, but what about the German-English dictionary case?

MS FADZEAN: Oh, my word.

MS McKENZIE: I hadn't expected - - -

MS McFADZEAN: That one is fascinating because we actually - it was remarkable. We had a circuit federal magistrate from Melbourne hearing the case from Perth with me being in Melbourne. It was just very bizarre. It was one of those incredible phone link-up situations. We're finding that very difficult. We're finding the publisher doesn't want to do it until every other publisher is required to do it. We're now in sort of negotiations where we think it might well settle, but it is - - -

MS McKENZIE: And every other publisher, of course, is not a party to the case.

MS McFADZEAN: Of course not, so you can't really argue - - -

MS McKENZIE: You can't require that.

MS McFADZEAN: We would think, if there was broad - it's not here. This isn't going to be the forum, but there would need to be significant reform of copyright law to make our way much easier in relation to this case. We would like to see something that we have seen in the US, which is a requirement that every publisher in Australia produce an accessible disk format of whatever work is published, which would make it a hell of a lot easier than having to go back to a typesetter who hasn't actually made the original document in a format that can be produced easily in an alternate format and trying to argue it. It's that kind of case where we argued that if there was something from the outset that meant that it could be easily produced, then it would be so much less expensive than trying to do what we're doing now, which is go back and say, "Can you please make an inaccessible document accessible?"

MS McKENZIE: Any retrofit is always going to be more costly.

MS DIAMOND: And under the HREOC tertiary education forum I talked of last year, one of the committees there is looking at copyright with that kind of - copyright is a big thing and I think not just in the field of education; just through general living, you know, for people who need material produced in accessible format.

MS McKENZIE: To the extent that this is an educative tool, do you know how the education standard would apply? I mean, assuming that it went through in the same form, would then basically the school be somehow required to produce that material in the accessible format?

MS McFADZEAN: Yes, unless of course they can't, in which case they get the defence of unjustifiable hardship which does still exist in the standard. What it will mean is that - I mean, at the moment many tertiary institutions, they ring the publisher and beg and say, "Please, please, please." But what happens here is that they give the disk to an individual student, so the next time they get a blind student that arrives who needs access to the same text, they've got to go to the same publisher and beg again. So rather than actually have processes which mean they develop a library of accessible tools, it all has to - they reinvent the wheel every time. But we find that, you know, in those circumstances where they can't get a disk, I mean, they'd be sending the document off to one of the other producers to be typed in and then put into the alternate format.

MS McKENZIE: So it would be massively expensive.

MS McFADZEAN: Massively expensive.

MS DIAMOND: Exactly, yes.

MS McFADZEAN: That's why we would like to see reform.

MS DIAMOND: Even in the National Library, you know the lodgment of electronic versions of everything published is certainly what I'd like to see happen and not just education material, as they do with any text produced at all, any book at all.

MS McFADZEAN: Imagine the market. Blind people would love to buy the latest Harry Potter. Why should they not?

MS DIAMOND: But it's not even just blind people. I mean, print disabled is of course as you know far more extensive than blindness.

MRS OWENS: And the technology is there.

MS DIAMOND: Yes, it is. Exactly.

MS McKENZIE: I think Helen is relieved I'm not asking more.

MRS OWENS: The time is ticking over and I can see the clock. Okay, we'll just break for a minute.

MRS OWENS: The next participant this morning is the ME/Chronic Fatigue Syndrome Association of Australia. Welcome, and thank you for the submission which we have now just received. For the transcript could you each give your name and position with the association.

MR MOLESWORTH: Good morning. My name is Simon Molesworth and I'm the national chairman of the association.

MRS OWENS: Thank you.

MS MILES: My name is Nola Miles. I'm the immediate past secretary and treasurer of the national association and I'm also the executive director of the CFS/ME Victoria.

MRS OWENS: Thank you. What I will do, given that we have just received the submission, I will hand over to you both and you can perhaps run us through some of the key points. We can read it all later, but if you can give us the key points and we can talk about them.

MR MOLESWORTH: Thank you very much, and may I start by apologising for the lateness of the submission. The submission effectively makes the critical point that we wish to submit, and there are a number of documents we can leave to inform the issues that are addressed in the submission. If I may start by just addressing who the association is; to explain. The ME/Chronic Fatigue Syndrome Association of Australia is an association comprising representatives of each of the state and territory ME/CFS societies and support groups in Australia, there being one or more in each Australian jurisdiction. The association represents at least 150,000 patients and carers in Australia who are experiencing the challenges of CFS on a daily basis.

Although the actual subscribing members of the association's societies comprise only about 5 per cent of the national patient estimate the provision of support and advocacy services throughout each year benefits many tens of thousands of Australians. The association has a critically important role to play in Australia in stimulating and coordinating nationwide efforts to achieve greater awareness of CFS and better support services with the condition. It is in this context that we make the submission.

The critical core issue. This submission addresses a critical core issue that the association requests the commission to address in its inquiry into the Disability Discrimination Act and that is the inconsistency between the definition of "disability" as it appears in section 4 of the Disability Discrimination Act with the definition of "disability" in other legislation throughout Australia. In circumstances where legislation throughout Australia - in particular in the various disability services acts in each jurisdiction - defines "disability" in an exclusionary fashion with the effect that, from a statutory - a definitional perspective CFS is not accepted by service providers as being a disability. The ability of patients to seek redress in response to discrimination is, at best, legally problematical and uncertain and, at worst, unavailable.

The ramifications of this situation has been to place the Disability Discrimination Act off limits to people suffering CFS as they generally have neither the financial resources nor the human physical resources of good health and staying power to commence the process to redress discrimination they have suffered. I think, members of the commission, it is probably appropriate if I give a brief description of CFS.

MRS OWENS: Thank you.

MS McKENZIE: Simon, we're Helen and Cate. We'll call you by your name, if you are happy about that.

MR MOLESWORTH: Thank you very much, Cate.

MS McKENZIE: This is a much more informal process.

MR MOLESWORTH: Thank you. Chronic fatigue syndrome - sometimes known as ME - myalgic encephalomyelophy or myalgic encephalomyelitis - is a serious disabling condition, which can effect people of all ages; classified by the World Health Organisation as a neurological disorder, being given the international classification of diseases ISD10G93.3. CFS simultaneously affects many systems of the body, giving rise to numerous symptoms, including persistent profound exhaustion, post-exertional fatigue, cognitive impairment, sleep disturbance, muscle and joint pain, headaches, digestive disorders, sensory dysfunction, flu-like symptoms, mild fevers, sore throat, irritability, sensitive to foods and chemicals, painful lymph nodes, heart palpitations and disturbance of balance and night sweats.

It would be fair to say that CFS is one of the most misunderstood illnesses a person could suffer. The level of incapacity experienced varies from individual to individual, but CFS is not diagnosed unless previous functional capacity has been reduced by at least 50 per cent for more than six months. Many people remain ambulatory, but are often unable to manage steps, long standing, or carry bags, and require extended sleep and rest periods. However the more severely affected are confined to wheelchairs and bed.

The symptoms fluctuate from day to day and hour to hour and are exacerbated by physical and/or mental exertion. For some, the level of exertion required before symptoms worsen is minimal. Moreover recovery from over-exertion is delayed and prolonged. There is no known cure for the disease. However by careful self-management of the illness people with CFS can maximise their functional capacity without causing serious deterioration. Some people make a reasonable recovery from CFS after a number of years but, for others, the condition follows a relapsing path or remains chronic.

I should say at this point that of the national association's board - which comprises 12 people - there are only two people on that board who have not had or have CFS. Of the 10 that have or have had it all have had it for a period in excess of six years and the majority have had it for an excess of 12 years and two have had it for an excess of 20 years, and I should say that the most extreme form - and we have a number within our Victorian society and the national association - probably it's in the order of 10 per cent - are people who have been bed-bound for a period of many years; often on life support with gastronasal feeding - or nasal gastric feeding - and saline drips, and are totally and utterly dependent on carers to live.

It is little understood that that order - that's a very large percentage of the CFS patients - are that disabled, and some of them have virtually given up hope by virtue of the fact that of the 10 trigger symptoms to identify the illness - if they have eight or nine their condition is almost without match. So it's an illness that when one hears - as Nola and I would well witness that we hear it often - "It's that illness where people are tired" or, "It's that illness where they're just malingerers," it can be very upsetting for those who have the illness. There is no known cure, as I have said.

The impact of incapacity. As a consequence of the severity of many of the symptoms of CFS it can severely affect those who have contracted it; for instance, those in the workplace can rarely maintain the level of productivity hitherto within their capacity, and many must leave employment altogether. The learning capacity of students living with the illness can be severely affected, limiting their ability to take part in educational programs that require regular attendance and sustained performance.

As a general overview, most people with CFS are challenged in just about every aspect of their life, so the simple task of negotiating public transport or the more complex challenges of maintaining personal financial viability can often become overwhelming. In such circumstances the individuals concerned then become reliant upon whatever support services they can access. Beyond the support of carers who might be available within their immediate circle of family and friends, it is when CFS patients seek the support of external providers or the understanding of those with whom they must interact, such as their employer or their insurer - if they are lucky enough to have taken out business employment insurance or superannuation or the like - that they then find discrimination often stands in their way.

The misunderstandings and definitional issues are the explanation. There is still much misunderstanding of CFS by medical practitioners and educators in Australia. The publication in March 2002 in the Medical Journal of Australia of the Royal Australasian College of Physicians, CFS Clinical Practice Guidelines, which was sponsored by Commonwealth funding, has reduced the problem of lack of knowledge and understanding in some areas but not to any meaningful, let alone desirable, extent.

The association believes that the guidelines, when read by persons with superficial knowledge of the illness, can lead to a misrepresentation of the illness and may lead to misdiagnosis, misunderstanding and inappropriate treatment. The guidelines are but one instance - but a very significant instance - of the problem arising out of the continual misunderstanding of the nature of CFS. Now comes the nub of the issue. Misunderstandings lead to definition problems and, in turn, those definitional problems lead to serious issues with respect to discussion support services.

Many of the serious issues which arise with respect to disability support - or rather, more accurately, the denial of such support - can amount to discrimination. In circumstances where discriminatory consequences flow from actions - or actions which are in effect sanctioned by legislation - due largely to exclusionary definitions of "disability", there is a distinct likelihood that the Disability Discrimination Act can be or will be of little assistance to the person disadvantaged by discrimination of the kind just described. I will explain that in a short while.

The inadequacy of accurate information on CFS in the community, combined with the lack of its recognition as a disability, means there is wide variation in the degree to which the disability-related needs of persons with CFS are accurately assessed. As a consequence there necessarily follows a wide variation in the level of support services available from both the public and private sector. Within the public sector we include the broadest range of services or support from the provision or non-provision of disability pensions to the provision or non-provision of consideration to students in educational institutions.

Within the private sector we also include the broadest range from the provision or non-provision of caring and tolerant work environments to the provision or denial of an insurance or superannuation payouts. If I can just interpose and say this: that in my experience now - which covers a period of eight years in the organisations - almost invariably a person who has contracted CFS finds that when they approach their insurer or their superannuation company they are rejected in the first instance.

Almost invariably they then have to commence the processes of review and appeal, which can mean all the way up to the various tribunals in those areas. Almost invariably the people so claiming support are without resources because they, inevitably, have ceased earning an income. They are inevitably people who are depleted in all physical energy, and often all mental energy, and they find that the task of tackling the insurance companies - which inevitably reject their claims on the basis that CFS is not a disability - is one that is almost overwhelming and, unfortunately, because the definition in the disability services legislation is incorporated in a range of other legislation by reference, those same people are confronted with what we describe as "discriminatory action and rejection".

I will give but one example. In the legislation in this state in relation to the taxi, the Taxi Directorate of Victoria has a specific reference to CFS in their guidelines for obtaining a taxi concession card, and it says, "CFS is not accepted as a disability for the purposes of obtaining a concession card." And when challenged, after a prolonged period of FOI and letters backwards and forwards, it was revealed that they rely upon the definition in the Disability Services Act and they, by the provisions of their own transport act, have the discretion to allow CFS people.

I have, within the members of the Victorian society, many hundreds of people who are unable to negotiate public transport, who require a taxi to come to their very door, who are without means because they no longer have employment, yet they cannot get a taxi concession card. Unfortunately they then have to play some other sort of game just to try and get someone to describe their illness as something else because, unless they get it described as something else, they are discriminated against. There is no appeal available because the taxi directorate relies on the Disability Discrimination Act.

MS McKENZIE: On the Disability Services Act.

MR MOLESWORTH: Exactly, and it's because the definition excludes CFS by reason of the reference to permanency. The problem associated with the recognition, and so the definition of CFS, has led to consequential problems with the drafting of legislation, procedures and guidelines in all jurisdictions across Australia. In most instances the definition problem manifests itself in the illness falling outside the statutory definition of a disability. It is this issue of CFS not being recognised in some legislation as a disability that forms the basis of the primary submission of this association to this inquiry into the act.

If I may interpose, when our members seek legal advice as to whether they have any chance to bring a review or proceedings under the Disability Discrimination Act, lawyer after lawyer says to them that because CFS is not defined as a disability under the other legislation, it doesn't matter that the wide definition under the Disability Discrimination Act might catch, we would say, CFS. It's because the rebuttal, the resistance, the defence by the party being brought to task says, "Well, there's much to say that CFS is not a disability," and our people can't - quite frankly can't embark upon those legal tussles.

CFS/ME Victoria, the society in Victoria, representing some 1800 members and some 15,000 or so people in Victoria with CFS, prepared a submission for the Victorian government titled Recognition of CFS and ME Disability, a submission to the Victorian government, addressing the problems associated with the lack of recognition of CFS as a disability under the definition of the Victorian Disability Services Act. The problems associated with the definition of disability in the Victorian act are common to most other jurisdictions in Australia.

In particular, under the Commonwealth Disability Service Act of 86 one finds in section 8 the specification of the target group of persons eligible for funding of disability services which excludes those whose disability is not permanent or likely to be permanent. In short, if the interpretation of disability is continually tied to permanency, then CFS patients will more than likely continue to be shut out from most of the available support services which would otherwise be available to them, and if I may interpose again, it doesn't matter how many doctors who specialise in CFS say that CFS is permanent, and no matter how many patients we have within our associations and societies which believe that it is permanent, having suffered some 20 years or 10 years or whatever period it might be. If it comes to the tussle from a legal definition point of view, they say there is no proof of permanency. If one has lost a limb, obviously the limb is not there, but if you happen to say you've got CFS, well, there are two sides to the medical debate.

In highlighting this aspect of permanency as a problem with respect to the definition of disability, the association does not need to argue that CFS is or is not permanent. That is for the medical researchers to one day establish. However, the association does argue that the absence of proof of permanency of the illness or the more extreme symptoms of the illness ought not operate so as to exclude the provision of disability services. This provision can be justifiably stressed to the greatest degree when it is understood that within the spectrum of persons suffering CFS, there are persons who are totally disabled, without any independent capacity to survive without constant and ongoing support.

In order to enable the Productivity Commission to better understand the significance of this issue regarding the definition of disability in the context of CFS, I now table with the submission a copy of the submission to the Victorian government prepared by the Victorian society regarding review of the Victorian Disability Service Act. Among the appendices to that submission are letters from nine medical practitioners specialising in the treatment of CFS, who set out their professional opinion regarding CFS as a serious disability.

The fact that CFS is not classified as a disability is out of step with the international recognition of the illness. In the US, the National Institute of Health, the Centres for Disease Control, Food and Drug Administration and the Social Security administration all recognise CFS as a serious, often disabling illness, and the level of funding of tens of millions of dollars recognises this. In Australia, the National Health and Medical Research Council recognises CFS as an organic physical disease, affecting up to 150,000 Australians, yet legislation throughout Australia continues to discriminate against CFS sufferers by effectively excluding them from many of the support services that would otherwise be available to them.

To illustrate this in just one area, that is, in the field of secondary education, in a report titled Just a Lazy Teenager, written in 2001 by Lesley-Anne Elbourne in her capacity as a member of the National Youth Roundtable, she revealed inadequacy and inequity between rural and metropolitan Victoria in support for students with CFS, and I table now a copy of Just a Lazy Teenager, the Elbourne report.

MS McKENZIE: Thank you.

MR MOLESWORTH: In rural and remote areas of Victoria, 78 per cent of young people who had left school because of CFS and were not in any form of education stated that their schools had not provided the support they needed. That's 78 per cent. And 11 per cent stated they were supported only some of the time. So that makes 89 per cent that one could legitimately say had a real complaint. This study by Ms Elbourne indicates that there is much scope for improvement in the level of provision of support for students with CFS in Victoria. It is anticipated that a similar situation is likely to occur in other parts of Australia.

This is the nub of this point: where the lack of provision of adequate support services can be traced back to a refusal by the schools concerned to accept the reality of CFS, there can be no doubt that these students suffering from the disability in reality, if not by legislative definition, were subjected to discrimination. Such discrimination ought to be capable of remedy, and I can interpose and say - and Nola will no doubt elaborate - that it is a regular source of a cry for help to our society and societies around Australia from students and parents saying, "The school is calling me a truant. They're saying I'm lazy, they're saying I'm dysfunctional within the school, yet I am ill and I can't continue, yet I have no understanding," and in some areas it can result in the student being removed from the school and without any remedy, when the cross-referencing between the legislation of different areas is to the Disability Services Act which defines CFS as not a disability.

The legal obstacles faced by CFS patients: I have now been working within the CFS support organisation of Australia for eight years, largely as the Victorian chairman and national president, and in that time I have been confronted with a myriad of instances of unacceptable circumstances confronting people with CFS throughout this country. I can't help but bring to my position the perspective of a barrister who has largely worked within the civil rights area, although always largely in the environmental field.

Without exaggeration, every month of those eight years I have been appalled at one example after another of some poor person struggling with their illness while being confronted with the additional burden of an unacceptable legal, bureaucratic or administrative block to them receiving the support, the care, the finance, the equal opportunity or just the basic dignity to go on as they should be entitled. I can elaborate, as indeed all the CFS societies around Australia could echo, about these problems, but it is sufficient for today to say, if the definitional issue regarding disability can be addressed so that people with CFS can be assured of an even playing field when they find it necessary to seek justice or just receive what should be their entitlements, then we will as a nation have addressed a very serious deficiency with respect to disability.

I'm afraid it is an issue which lives with us daily. It is an issue where people ask us whether they can or should commence a Disability Discrimination Act review, and time and time again they have sought private legal opinion or they have sought the advice of people such as myself, or they have observed the few - and they are rare - instances of people endeavouring to bring reviews under the Disability Discrimination Act, and they have found that the response has been that they have not been able to find a remedy because the insurance industry is terribly sensitive to this area. We have found that employers are terribly sensitive in this area.

We have found that some educational institutions - some are brilliant, and in fact within some, one can move from faculty to faculty. Within Melbourne University, one faculty is known to be excellent, another is appalling. Every year one faculty - we have at least one student who has had to leave their tertiary studies because of the attitude adopted by that particular institution.

MS McKENZIE: So they won't allow them time, they won't allow them to do - - -

MR MOLESWORTH: Exactly, any of the normal that's provided, and they have appealed through the processes within the university and at the end of the day a smart person produces a definition which is not supportive of CFS being a disability, and it may be a lawyer, it may be an administrative person or it may be an insurance advocate. It's a crisis for us. We have been endeavouring to set up a pro bono legal panel across Australia here; we've been trying to train lawyers to understand CFS. We, with our few resources, have found a challenge in doing that, and those that we have working within our team have more than they can cope with, and it is a challenge of the utmost seriousness. So that's the submission. There are the support documents.

MRS OWENS: Thank you very much for both - the submission and the documents. I know you have to go.

MR MOLESWORTH: I do apologise for that.

MRS OWENS: No. But if you don't mind, we might press on and have a discussion.

MR MOLESWORTH: Please do. Nola is one of the most experienced people within the CFS area in this country. She probably doesn't mind me saying that she has had CFS herself for many years, and I think it would be fair to say that she carries out onerous and important responsibilities in this country, despite having occasional relapses. She is the good side of CFS. She's a capable, competent individual, fighting for 150,000 other people in this country. So can I thank you both for hearing me.

MRS OWENS: Thank you. Just before you go, I think there's probably no doubt - "probably no doubt" is probably not the right way to say that - that the Disability Discrimination Act definition is sufficiently broad that it would pick it up.

MR MOLESWORTH: It is.

MRS OWENS: So I don't think there's any doubt there. It's just a matter of what you could do once you're into a complaint under that act - how successful it would be. If it's a complaint about a service, a government service, there's a question mark there. But if it was a complaint relating to an educational institution or an employer, well, that's - - -

MR MOLESWORTH: I would have thought so. I know a test case is being commenced now in Sydney by a student who has now finally completed his university education, but it has been a traumatic experience of the worst kind, and he is now commencing the steps under the Disability Discrimination Act. But he has qualified himself in law, and I think three lawyers who have all had CFS have now grouped together as a specialist firm to try and help in this field.

MS McKENZIE: But even though you say the DDA might cover the definition of disability, is there still a problem in that - whatever the international classifications say. Is there still medical evidence that respondents could bring which says, "This is not a disability within the meaning of the act; it's not a medical condition that we recognise"?

MR MOLESWORTH: Yes. It would be fair to say the debate is a heated one. The Australian Society of Psychiatrists seek to establish that the illness is a somatisation disorder - that is, an invention - and as a consequence of that, authorities within the disability services area have been cognisant of that debate and have said, "Well, look, if this illness doesn't actually exist, therefore how can we accept is as being a disability?"

MS McKENZIE: So there could be a problem actually for the definition - - -

MRS OWENS: Although the Australian Institute of Health and Welfare, I think, has recognised it in its work; NH and MRC, I think, has recognised it. I don't know what's been picked up in our ICD code in Australia, but you said in your submission it's been picked up in ICD10.

MR MOLESWORTH: It has.

MRS OWENS: And I'm not sure what's been picked up in our code here. But I think - well, there's a question mark.

MR MOLESWORTH: There is.

MRS OWENS: But it's such a broad definition, and the reason it's so broad is to stop the argy-bargy about these sorts of issues.

MR MOLESWORTH: Exactly, and I would have thought there is ample ground, but our experience has been a sad one. The fact is, irrespective of the debate, the societies say that there can be no doubt that however you characterise the illness, it is so patently clear that the person is seriously ill that how can it be argued - even if it's for six months or a year or two years or three years - that it's not a severe disability.

People like myself, I had - one of my children was at the most severe end and was being kept alive on life support. He missed five and a half years of school, but at its worst no-one had an expectation that he would survive. Now, to then be confronted with people saying it's not an illness, or it's not a disability, is more than anyone can take. It's an extraordinary situation that we now get referrals of people crying for help, confronted with bureaucratic rejection.

MRS OWENS: But you do say - and this is my understanding as well - that the NH and MRC, the National Health and Medical Research Council, which is an Australian government body, is recognising CFS.

MR MOLESWORTH: Yes.

MRS OWENS: So that's a fairly strong argument as to why it would get picked up. I don't think, if you brought a case under the DDA, that people could say, "Well, the NH and MRC has got that wrong."

MR MOLESWORTH: I would entirely agree with you. But unfortunately the actions that are taken in the work care area and in the insurance review area inevitably have, with the resisting party, an advocate - be it lawyer or whoever - producing medical witnesses to say, "Well, there is evidence that this illness doesn't exist," and the outrage of that is terribly upsetting for our societies and our members.

MRS OWENS: I think it's very convenient for certain groups to argue that.

MR MOLESWORTH: Yes. Financially it's in their interest.

MRS OWENS: We'll have a look at this. But we'll carry on with Nola just for a few more minutes before we have a break.

MR MOLESWORTH: Thank you very much.

MRS OWENS: Thanks for coming.

MS McKENZIE: Thank you very much. Thank you for coming.

MRS OWENS: Now, Simon mentioned this test case that's about to take place, or is taking place. Have there been any other complaints that have managed to get through the system, or have been started, Nola? Do you know?

MS MILES: Not that I'm aware of, inasmuch as I can't actually speak for everyone, because we don't have the resources to keep track of everything.

MRS OWENS: No. I was just wondering whether there had been any attempt to actually get something into HREOC, the Human Rights Equal Opportunity Commission, to see what their response would be to a complaint.

MS MILES: Again, it's a lack of resources that that hasn't occurred as yet, basically.

MRS OWENS: But also, from what Simon was saying, it's also that there are real difficulties with people who suffer from this condition actually running a complaint.

MS MILES: Absolutely. I mean, someone that's bedridden and has no mental capacity to do anything, how can they run a complaint, especially if they have no legal background. They haven't got the energy, physically or mentally, to actually do anything.

MRS OWENS: And that would present difficulties if the complaint - well, even, for example, to go to conciliation, where you might have to - there would have to be some special accommodations made, because you would not be able to sit for a whole day discussing that.

MS MILES: No. People can't even sit for a couple of hours.

MRS OWENS: And you might not be able to turn up on the day it's scheduled anyway.

MS MILES: No. The problem with CFS is that it is fluctuating and so you can't even tell one day to the next whether you'll actually be well enough tomorrow to attend at 10 o'clock or whatever. So there's that problem as well. You may find that you wake up in the morning and you can't get out of bed, and it's that very variation that therefore people misunderstand what the illness is, because they see someone out one day that appears fine - perhaps had to go down to the shop and buy some milk or something - "Well, you were out yesterday. Why can't you get out today?" and it just doesn't occur.

MRS OWENS: Can I just clarify something about the illness. In some cases it's triggered by - like Epstein-Barr virus?

MS MILES: Yes. They don't really know what causes it, but it's triggered by any sort of stress, and when I say "stress" I mean physical stress on the body, such as a virus, or an event - a major event, and it could be just any sort of stressful thing that happens, be it medical or physical or whatever. So they don't even really know what sort of triggers it, but everything can - anything at all that causes some stress on the body can actually trigger it.

MRS OWENS: And then the immune system is affected.

MS MILES: Well, yes, in some people. They really don't even understand exactly what's going on, because there's no research really being done conclusively into any area of CFS that's really of any significance; it's ad hoc. I've approached the NH and MRC to find out why they can't put more money into research and get it listed on the Strategic Research Development Committee, and they just rejected it because they said there was - they did peer review, but the unfortunate part with peer review is, if there's no-one expert in CFS, or they rely on the psychiatric peer review of CFS, no physiological research will get done.

MS McKENZIE: So what's the attitude of the NH and MRC? They do regard this as a medically-recognised condition. Is that right or is that not right?

MS MILES: I'm confused about what they do recognise. On the one hand they do acknowledge, and everyone acknowledges that this is a serious illness, but when you get down to the nitty-gritty and actually say, "Well, can you give us some support, research?" whatever, you get the, "Oh, well, no." There's just this block, and I find that that's in all areas, including funding from state government. They're all very supportive and say they recognise the illness as serious, but that's as far as anything ever goes; it just stops.

MRS OWENS: I've been on NH and MRC - I've been involved in reviewing submissions in NH and MRC, and like all organisations, they've got a limited amount of money and they allocate resources according to a whole range of criteria. So that's not - not that they're not recognising the disease, it's just that they've got a whole lot of other priorities as well.

MS MILES: Absolutely, but - - -

MRS OWENS: But you've got to have the researchers that want to take it through as well.

MS MILES: One of the problems that I see in that is - sorry, I've lost my train of thought. The NH and MRC actually does - and I understand it has a finite amount of money - but we're not arguing for all of the money, we're just arguing for a balance of any money that they do put in, to ensure that research is done into the physiological aspects, rather than concentrating on the psychiatric ones and/or just recognise that this is an area of medicine or research that is becoming more recognised in the community, and it needs to actually have a relevant amount of research funding targeted towards it.

MRS OWENS: But for a minute just leaving the question of priorities and funding for research aside, they do recognise this as an illness, as a medically-recognised illness.

MS MILES: Yes, but again, it's a case of the perceptions. I have heard anecdotal evidence that researchers - because there's a lot of work involved in putting a submission to get it to the NH and MRC, they know what the outcome is going to be, so they don't bother applying. Now, this is something we need to redress, but again, the societies don't have the resources to encourage researchers to apply.

MRS OWENS: But there has been quite a lot of work done in the US through the

National Institute of Health as well, so there must be a body of evidence being built up in the literature by now.

MS MILES: Yes, and perhaps that's where the next resources need to go, and that is to collect all the evidence together and see what the threads are, because it is so - many studies are done on small groups, and they don't come out - the studies can't be reproduced because they're small groups. One of the problems with CFS/ME is that most people in support groups recognise that it is probably an umbrella term for a number of different illnesses, and of course if you mix illnesses, you're not going to get the same result in any two research studies. So that's an area that - you know, a group of people could actually be under one subset and the next group of researching could be done on some entirely different illness, although it's termed CFS/ME. But I do believe they'll probably find subsets in that area, but unfortunately at this stage that doesn't help the people who are suffering CFS/ME now.

MS McKENZIE: Can I ask just a few more questions about employment and education, because Simon raised them. Has the association had any negotiations with employers, where your members have found it difficult having ME/CFS - found it difficult in employment? Have you had any discussions with employers looking to try to perhaps change work practices to accommodate?

MS MILES: Again, I think you need to understand that the society is actually very small. The turnover for the national association is something like $4000 a year. The Victorian society gets $30,000 from the Victorian government to look after something - the latest - if you use the RACP guidelines, .7 per cent, there's 34,000 Victorians with CFS/ME and we get $30,000 from the government.

MRS OWENS: Isn't that interesting; they give you money for the society, but they don't - the Victorian government doesn't recognise you in the act.

MS MILES: They give it to us out of the public health. They will not give us any money under the Disability Services Act.

MRS OWENS: Isn't there a degree of inconsistency in the government's approach? I would have thought so.

MS MILES: Well, again, there's this wall. We get very supportive support from MPs, the minister for health recognises it. Once we get past - and the submission there shows - once we put the submission in, we don't get to speak to anyone. I tried the entire time last year to actually approach Arthur Rogers and various people in the Disability Services Act, and what I actually got was, he wrote me a letter and said, "Please see the acting director of policy and planning." I saw her.

She undertook to get back to me within four weeks, to investigate anywhere we could apply for funding. She had another assistant with her at the time of the meeting. She said she would get back to us within four weeks. Well, unfortunately the four weeks was up, she had left the department, and the other lady was on leave but she wouldn't be back for another few weeks.

In that time, I contacted them again - she had already left the department, and the new people in there had no follow-up, and all - they got back to us and said, "Well, you were right. We can't find you any funding and the Taxi Directorate says that you're specifically excluded." That's as far as we get, and with the amount of money and effort that we try and put in to actually also providing services for our members, we don't have the resources to actually help our members to go that extra step to actually do these things. It's just impossible.

MS McKENZIE: I can understand.

MS MILES: It's just impossible. Basically, $30,000 doesn't cover our rent and our phone calls and running costs and yet we have no full-time paid staff. It's just the absolute lack of resources and it's a vicious circle: because we have no resources we can't put together assistance for members in these areas.

MRS OWENS: Yes. I think we have probably covered what we can today with you, but we are very grateful for the submission and for you coming along today.

MS McKENZIE: And the extra documents which you have brought, too. That will be very helpful for us.

MS MILES: Yes, okay. Simon has left them there on the table.

MRS OWENS: Yes, thank you.

MS McKENZIE: Is there anything else you want to raise before - - -

MS MILES: Probably not, although I suppose from the CFS/ME point of view, people are really frustrated that they feel if they had a different illness they would get better recognition. That's the really frustrating part - that they're as sick or as impaired as very, very serious - especially the severe end, probably more severe than anything else, and yet they're sort of not being given any support at all. That's what we're trying to get - at least equal support for equal impairment.

MRS OWENS: Good, thank you.

MS McKENZIE: Thank you very much.

MRS OWENS: We'll now break until 20 past 11.

MRS OWENS: We will now resume and the next participant this morning is Disability Rights Victoria. Welcome, and thank you for your submission. For the transcript could you each give your name and the capacity in which you are appearing.

MR CRAIG: I am David Craig, executive officer with Action For Community Living. Action For Community Living is the auspice organisation for the Disability Rights Victoria consortium of advocacy groups.

MR SMITH: Graham Smith, chairperson of Disability Resources Centre, one of the members of the management of the Disability Rights Victoria network and also a provider of individual advocacy services. I also happen to be the community representative for education standards on the DDA Standards Project, so I have been one of the two community representatives involved in the development of education standards under the DDA.

MR EICKE: My name is Steven Eicke. I'm the current chairperson of Disability Rights Victoria and I'm public officer of Aged Community Living.

MRS OWENS: Good, thank you. Which of you would like to introduce your submissions? Is it going to be Dave?

MR CRAIG: I'll do that, yes.

MRS OWENS: Thanks, David.

MS McKENZIE: We're Cate and Helen. We'll call you by your names, if you are happy about that, and so you call us by ours.

MR CRAIG: That's right, yes. Just very briefly, I suppose, an overview of the submission we have made. We have tried to point out that having the DDA has provided a framework that people previously didn't have and it is certainly a significant improvement on that. In looking at the things that we feel are weaknesses or limitations, we wish to reinforce that having an act there that can be used to help people deal with issues of discrimination has certainly been a useful framework for people to work with.

A major concern we have is that for many people with disabilities - particularly those who rely on support for their day-to-day existence - the capacity to get out and about in the community is limited by the nature of the resourcing which still tends to institutionalise many people with disabilities, or people on waiting lists for services and resources to be able to get out and about in the community, and the lack of participation and active engagement in the community means that they haven't even really got to first base to experience perhaps the nature of discrimination, let alone get the confidence and the support to follow through and deal with it.

There are also some concerns about some specific limitations that the act has in relation to how confident and how supported people feel in terms of using it as an act and there are, unfortunately, probably too many stories that circulate of people who have made attempts to use the act and have been frustrated by either the length of the process or the sense of the odds they face, as an individual, by the system, and the limited capacity to find supports in the community through advocacy or other support organisations. Some limitations as to what the act covers - we will address that as we go through and talk about it, but specifically, I suppose, concern that it doesn't really cover the scope of rights that people are really concerned about. Graham will speak probably in a little more detail about that issue.

We're also concerned at the lack of education and support resources for people to know how to use it. We're aware, for instance, that in the US, with the Americans With Disability Act, there was quite a significant campaign of education and resourcing and supporting people to actually begin to exercise the act in a very practical way that led to - one of the reasons why we think there was probably a much more effective use of the act than there has been certainly in Victoria.

We would just like to make some comments about the sorts of choices people have to make around using one act or the other; that there is a state Equal Opportunities Act; there is the DDA. In my experience, as someone who supports people going through this process, people have tended to use the Equal Opportunity Act as a way that is certainly more expedient and certainly user-friendly, but concerns still exist around both acts about issues such as mediation, the confidentiality of mediated arrangements, a lack of that having any real systemic impact or raising awareness in the community about what can be achieved through the act and, where there are agreements that are mediated, a lack of serious compliance. There is little pressure or expectation that people have to really comply with it.

Finally, around compliance. There seems to be a fairly gung-ho mentality within the business and private sectors in the way they respond to the DDA - that unless people are really active and vigilant in pushing their case, there seems to be enough advantages in avoiding having to meet or comply with the DDA and risk - or a complaint being taken, because the costs of having to deal with that seem to outweigh the costs from many of the operators of actually considering those issues at the planning or implementation stage of either building a building or developing a service.

They're things, I suppose, we've picked up through a lot of the work we've done with people. We're involved as an advocacy organisation, obviously trying to deal with some of these issues before they get to that point and it seems that many people probably use advocacy support processes more readily than they will use the legislative processes, and maybe the advocacy sector hasn't used this legal framework as much as they might. That picks up some of the key points we would like to make, but we're certainly open to have discussion with you about the submission in full.

MS McKENZIE: Do Graham and Steven want to say some introductory things before we go to discussion?

MR SMITH: Yes. There are some specific points I would like to make which perhaps go further than the submission we have put so far. I apologise for not having put something in writing but, being involved in the education standards process, I have sort of been snowed under with work in that area and, as you will be aware, the federal education minister finally decided to unilaterally legislate on education standards last Friday. We have done a significant amount of contacting national disability groups and informing them about the issues before that and trying to get them to lobby state ministers and so on with the issues associated with standards, but now we have at least got the federal minister unilaterally prepared to go ahead with that.

I was also pleased to hear in the corridors outside that you have access to the costs benefit analysis which has been done and which indicates some of the problems associated with education standards and the way they have been developed. Some indication of the amount of procrastination and obfuscation that has gone on in the process of development, where we have only had two community representatives on a committee of some 24 - 22 bureaucrats representing jurisdictions from around the Commonwealth - it has been a very difficult process and it has fallen very heavily on those two representatives and the small team that we've had assisting us.

It means that within the disability sector perhaps there are only a few people who know intimately what the process of development of the education standards has been and who are going to now have to work very hard on communicating the new answers and the reasons for particular parts of the education standards being the way they are - communicating that to the sector as the education standards come into force.

MRS OWENS: That will put quite a lot of the burden back on you and your fellow community person in that process, won't it, to really educate those people.

MR SMITH: Exactly. We were very pleased in Perth that the education minister committed to providing us with funds for community education, which was not one of the costs that was itemised in the cost benefit analysis and we see that as being a vital component now of introduction of the education standards because, unless our constituents know how to use the consultation processes that are necessary for the standards - that the providers have to undertake in the standards - unless our constituents know what they need to ask for and know how those processes work, they won't get to first base in terms of getting an education on the same basis as other students and we'll have the same problems that we have at the moment, documented to some extent in the cost benefit analysis - that many providers do not comply with the DDA, even though they claim they do. They are perhaps paying lip service to it. The problem with the DDA is that it's not until a complaint is made that it becomes apparent that there has not been compliance. It's not until it actually goes into the legal process, because the conciliation process is private and doesn't set legal precedents.

MS McKENZIE: Won't that be the same with the standards? How will you know if there has been compliance?

MR SMITH: That is a very difficult question to answer. The same complaints process applies.

MS McKENZIE: Yes.

MR SMITH: The standards project tried very hard to get a commitment to a user-friendly complaints process - that is described briefly in the guidance notes - but we were told quite firmly that a user-friendly complaints process that could resolve complaints prior to it going into the Human Rights Commission and the conciliation process or whatever, simply wasn't possible to be legislated for, but it's still an option for education providers.

MRS OWENS: Sorry, we are interrupting.

MR SMITH: That's all right.

MRS OWENS: Was there any argument at the time you were involved in the standards project about having some sort of monitoring arrangement - that HREOC would monitor compliance with the standards - or was that not something that was thought about?

MR SMITH: It's not a subject that has been raised. My view would be that it would have been expected that HREOC would be monitoring it in the same way that it monitors the DDA through putting out its annual report and so on.

MRS OWENS: You see, David raised the issue earlier about lack of compliance with some conciliated agreements and the same concern could equally well apply to lack of compliance with the standards unless there's some other process that follows on from the standards or from conciliation that takes you further.

MR CRAIG: One of the useful things about having greater specificity in standards - I mean, the standards can weaken and water down, I think, some of the rights-based elements of an act, and I think with the transport standards we have some examples where you know there has been some compromise between industry and the sector that may have compromised rights that are stated in the act. The education standards clearly, as a set of standards, seem to be saying what the act says in more specific terms and yet the authorities in seeing that - the Education Departments in seeing that - have been more sort of concerned than when they saw the act, so clearly it sort of specifies more clearly what compliance ought to be, and I think it helps in accountability.

It's interesting with the auditor-general's report on the Intellectual Disability Persons Services Act in Victoria that there was a mechanism that came out with quite a critical report and where in parliament there is a requirement to respond to that report and to get a departmental response that says what they will do in relation to recommendations and so on, so that was an interesting report and, I suppose, framework for looking at perhaps insurance and compliance, but mechanisms for compliance would be a critical factor.

Local government, we believe, should play a much more active role and have a legislative responsibility in ensuring that some of the building permits and planning permits processes are properly followed through because there are so many examples of new buildings being built for which councils don't even know whether or not a building permit was obtained and whether it complied and so on, and there is certainly nothing in the way of serious sanctions for people who give building permits that don't comply with existing building codes or the DDA. That's I think the issue: that even if what's there is good it certainly means little if it doesn't have serious ramifications if people don't comply.

The standard, certainly, of education seemed to have given a descriptive set of statements about what compliance means, I think. I don't think it has actually said anything radically different to what is already in the act but the act must be, obviously, not specific enough for people to take it seriously.

MRS OWENS: It says more about unjustifiable hardship too, as a standard.

MR SMITH: The issue of unjustifiable hardship is one that, to an extent, has been misunderstood, I think, in the sector - to an extent - because under the act the unjustifiable hardship clause only applies at the time of enrolment, but the way that

that has been interpreted under a decision by Graeme Innes is that an education provider can make a prediction for the first six years about whether they will experience unjustifiable hardship or not. Under the standards and the apparent intent by the minister to legislate, we hope, at the same time as the standards go through and not before the standards go through, the way the states want the legislation to go, because the passage of the two need to be linked together. There's a danger in not linking them.

Under the extension of unjustifiable hardship to the four areas of the standards to which they apply, what that means is that a provider will have to make adjustments up to the level of unjustifiable hardship in all those areas and they can only use unjustifiable hardship as a defence for discriminating if they believe they cannot make the adjustments required. The large providers, the statewide providers, have indicated, in the committees that I've been on, that they doubt whether they will be able to use unjustifiable hardship as an effective defence because of the amount of resources available to a large education provider. They have indicated, in those committees, that it will be the smaller independent schools, for example, that would be likely to use that provision. What it actually means, when it comes to legal interpretation, we'll have to wait and see.

MRS OWENS: So an individual state school couldn't run unjustifiable hardship because the overall department could be covering that cost.

MR SMITH: That's correct. That's the way that it seems to be being interpreted at the moment.

MRS OWENS: So there's going to be an amendment to the legislation as well as - or when the standards - - -

MR SMITH: That is the intent of the minister. That is what has been flagged by some of the motions that were passed at MCEETYA. The minister's statement didn't actually indicate that but I don't believe that there is much dispute that there be some changes to the act. The DDA Standards Project is in the process of writing to the attorney-general, indicating that the disability sector must be consulted about any changes to the act that occurs, as well as the states being consulted.

MRS OWENS: So there is still some little way to go in the whole process, in other words.

MR SMITH: There is some way to go. If the standards go through in the spring session of parliament, it may be that they will not come into operation until some time next year. It would be doubtful that they would be effective for the 1994 enrolment anyway because - - -

MRS OWENS: 2004, yes.

MR SMITH: 2004 enrolment - because many of the jurisdictions start finding the resources for new enrolment, the specialised resources and so on, from October or November or thereabouts. There simply wouldn't be the time to do the professional development and make the changes necessary to apply the standards at that point. It was on that basis that we negotiated with Minister Nelson to have the standards come in and allowed a short time frame for professional development and for community education that was funded by (indistinct) in Perth. We're very pleased that he has provided that funding for community education.

MRS OWENS: You said that wasn't in the initial - - -

MR SMITH: It's not in the cost-benefit analysis, no.

MRS OWENS: Did you lobby for that? Did you ask for that or did it - - -

MR SMITH: Not during the cost-benefit analysis process.

MRS OWENS: But in subsequent meetings you said, "This should be a necessary part of the process."

MR SMITH: In the lobbying we did in Perth, that was. Some of the dangers that I see in the education standards arise from the nature of support that will be provided for students with disabilities because there has been a past history of provision of support for students with disabilities by simply providing them with teacher aides and then the teacher aides become one of the primary factors in discrimination within the education system because they take the child aside and teach the child separately. I see a danger that many schools and teachers and parents see an aide as being the resource that they are going to press for under the standards because in some cases the aide, in the past, has been the only resource that has been available.

What the standards do not do and perhaps were not able to do is define the way that professional development should be provided for teachers so that they can teach to diversity and be able to teach all children, those with disabilities and those without disabilities, in the same classroom. That professional development is sadly lacking and education standards, I don't believe - we certainly weren't able to have included any clauses that are able to address how that should be done.

MRS OWENS: Maybe once the standards are introduced, the professional development - if they're being implemented properly - state governments or education providers will recognise that certain things need to happen to ensure that the standards are properly implemented and it will flow through. Maybe it will just flow through. Maybe I'm being optimistic.

MR SMITH: Put it this way. The response of Tasmania throughout the process has been very interesting. They already have negotiations with their teacher training institutions and some of their teacher training institutions are trying to address this problem so their view of the costs of introducing the standards was that the costs would be very low. In Victoria I don't believe that we have had much in the way of professional development around teaching diversity since 1992 and perhaps that explains some of the fears that are developing around the Victorian bureaucracy about the costs of implementing standards and the amount of consultation that will have to be done and so on.

MS McKENZIE: But is it fair to say that there is a commitment through a combination of Commonwealth and state governments and territories funding to back the standards?

MR SMITH: There is a commitment from the state and territory ministers and the Commonwealth minister, to back the standards. It's a question, perhaps, of how they're implemented, that I'm flagging a danger, and we will have to wait and see how that challenge is taken up. The real problem with the DDA and education standards is that they are tools to address discrimination and if there is good education practice, then the standards may well be very effective. Where there is poor education practice, the standards only ensure that students are educated on the same basis as students without disabilities and so they will still receive poor education.

I think that where there is poor education practice, it is usually the students with the lower ability levels, the students who present problems, who are the ones who have the most difficulty. So educational standards don't address rights, as such. They only address discrimination. That, we could say, is also a broader statement about the whole of the DDA.

MRS OWENS: You made that point very strongly in your submission too.

MR SMITH: In determining discrimination, it being a very tight legal concept, there are issues like the fact that you have to compare a person with a disability against a notional, able-bodied person.

MRS OWENS: Yes.

MR SMITH: If you are a person with a disability in a segregated setting like an employment service or a special school, then it is very difficult to locate a notional adult because - - -

MS McKENZIE: Because of the nature of the service, yes.

MR SMITH: - - - an able-bodied person is not able to enter that service.

MRS OWENS: Yes.

MR SMITH: There is a significant issue there.

MRS OWENS: Yes.

MR SMITH: I wanted to say a couple of words about the transport standards just from personal experience of having a complaint in the process of settlement at the moment.

MRS OWENS: Is this your own complaint?

MR SMITH: This was a personal complaint. It was made about early model, low-floor buses which, it turns out, with one particular operator, there are 23 of them. They were introduced after 1992 but before the transport standards were developed and they do not have aisles that are wide enough for someone in a chair my size to move in the bus and they also did not have ramps of any sort.

MRS OWENS: So they were low-floor but no ramp and narrow aisles.

MR SMITH: Narrow aisles.

MRS OWENS: Is there anywhere for you to go in the bus?

MR SMITH: Yes, there is a space at the back of the bus which would be suitable. I made a complaint about those - I think the sector was unaware that those buses were inaccessible because no-one had reported it to us. I discovered this when I had a broken leg and had to use public transport because I couldn't get in the car. I lodged a complaint just before the transport standards came into operation. My point is that there is a logical solution and that is the solution that they have adopted with the Adelaide buses, to have a ramp at the back door.

After lodging my complaint I received responses from the bus company and the Department of Infrastructure that they were not prepared to consider it because they considered it an unjustifiable hardship and unreasonable, and they did not consider that - I don't have the exact wording but they didn't consider that there was a possibility of a decision in my favour. I received informal advice from the Human

Rights Commission that because the bus company complied with the standards in having quite a number of other low-floor buses, they more than complied with the standards; that the conciliators of the Human Rights Commission had been advised to take that into account in any conciliation and that it would be doubtful if I would win the case.

I received similar advice from the solicitor at the local legal service. However, I left my complaint in place, despite that advice, and I heard last week that the Department of Infrastructure is funding the bus company to install lifts at the back door, or install ramps at the back door. I suppose my point is that it's very difficult to lodge - that the transport standards in that case worked against me dealing with a situation where buses that were clearly not compliant with the act when they were introduced - the standards acted against me making an effective complaint against that and it was only the goodwill, I think, of the Department of Infrastructure, that has resolved it.

MS McKENZIE: That was because the standards didn't require 100 per cent compliance at that stage?

MR SMITH: No. That's because the standards set a certain number of buses, a certain percentage of buses that had to be - - -

MRS OWENS: Yes, but not all.

MR SMITH: But not all. My other point is that this also raises the issue that operators may still purchase inaccessible vehicles, providing they have the required percentage of accessible vehicles at the particular time frames. There's no requirement under the standards for all new vehicles to be accessible.

MRS OWENS: Are they doing that? Because they're meant to move towards full compliance after a certain period of time. Why wouldn't the operators, when they're purchasing a bus, just get accessible buses and be done with it?

MS McKENZIE: They might just purchase a number. It depends on the cost. If the cost were greater, they might decide to simply purchase the number that was needed to comply at the relevant time and, in other words, do it over time. That's what the standards permit.

MR SMITH: And providers recycle their buses over a 10-year time frame. It may be that some providers - the little shuttle buses that they use for dial-a-bus services or issues like that - there have been inaccessible buses of that nature bought since the DDA. It may well be that some providers who have low-floor buses on major routes will operate those small buses or purchase new buses to operate on the minor routes which are inaccessible. It's a danger I see in the way that the standards have been framed. I'm just raising that as an issue.

MR CRAIG: I suppose, broadly speaking, that whole notion that once you have a disability action plan, you tend to be exempt to a certain extent from having to respond more specifically and certainly to the satisfaction of a complainant about a particular issue. I think the same applies beyond the transport area, that there tends to be a sense that if you have a disability action plan there's not much thought about how good it is, how specific it is and whether there's any accountability of monitoring it, whether it's been delivered on within the time lines committed.

We've collected and looked at a lot of disability action plans that have been put together by local government, and the quality of those disability action plans is quite variable. There's certainly some very ordinary stuff. One disability action plan that was reported to us had little action taken over the three years it was in place because no-one had been specified in the plan to take responsibility for it - you know, no particular department or person within the council.

MS McKENZIE: And there was no monitoring irrespective of whether people had been - there was no general monitoring by councils, for example - - -

MR CRAIG: No.

MS McKENZIE: - - - whose ultimate responsibility it should be.

MR CRAIG: Not unless people with disabilities become activist and voluntarily take up that role do those things tend to be taken too seriously.

MR EICKE: In which area of - - -

MRS OWENS: I'm sorry, Steven. Sorry, we kept distracting these two.

MS McKENZIE: We got sort of waylaid slightly by standards.

MRS OWENS: I hadn't forgotten about you.

MR EICKE: Disability Rights Victoria is a consortium of four groups but we contract out to network and we contract out to various regions of the health - or human services to do things like that, and then they have only a limited time where people in Geelong, Warrnambool, Ararat, Ballarat - Bendigo, sorry - Bendigo, Mildura, Shepparton, Wodonga and Gippsland, and they are employed to do that, and they have in fact set up committees in towns. Like in Gippsland there's Leongatha, Wonthaggi, Moe, Sale, Bairnsdale - have I missed one? Warragul, and they keep an eye on their committees. I know in the Hume region - they have committees in Beechworth and Wangaratta, Wodonga that look at their council and keep their council up to scratch. Each council has a disability advisory committee. Now, in many cases the disability advisory committees are just part of the furniture and they don't sort of keep a great watch - - -

MR CRAIG: The point is, if you give us advice, we don't have to take it.

MRS OWENS: Yes, okay.

MR EICKE: I was on the disability advisory committee in our local council 20 years ago, and we did a bit, but we didn't do much, because it's very hard to get people with disabilities involved, and that's the one of the things that I wanted to bring up about the Disability Discrimination Act, that sure, there might be one in five, as I noted in the issues paper, that one in five people say have a disability, but the groups in this paper, the groups that are going to appear before you that I've seen in your listings for this week probably only represent 3, maybe 4 per cent of those people, and nobody - well, I won't say nobody, but very few people know that there really is a Disability Discrimination Act there. They don't know what their entitlements are.

MS McKENZIE: Not just in the community in general but in the disability sector as well?

MR EICKE: Yes. I know this because I mix very freely with the community. I go to see plays, I see pictures, I see about 20 plays a year, I see so many concerts a year, and I get out, and I'm just regarded as someone who's just slightly off. People think yes, well, I'm a special case. I'm not a special case. I have a right to be there. In the issues paper you mentioned there that a person with a disability should not have to show a card or show justification for entry, but a person without a disability - I have to get it right - a person without a disability doesn't.

MS McKENZIE: Yes.

MR EICKE: Now, I was at the Cox Plate a year and a half ago, two years ago, and I was with a group of my friends that had been drinking. All the others were let into the interior except me. I got called back, held back, and I said, "No. No way, mate. I've got this and this." They said, "No, I'm not letting you in." So I stood there and I said, "All right, who else aren't you going to let in?" and so it caused a bit of an upset because he wouldn't let in a few other people, on the grounds that they were drunk, and they said, "How dare you call me drunk?" and I said, "Thank you."

Yes, anyway, back to the Disability Rights Victoria thing. We get feedback from the country all the time. We were actually at a meeting in Bendigo yesterday with the Victorian Rural Access Network. We had people there, some of the contracted staff who have been working for the last four years, and I was just going over with them, and we get the same old same old, but we get the reports based around certain issues, based around access, based around rights, based around transport needs and things like that, but the issue of having a Disability Discrimination Act doesn't come into it.

The issues of disabled people having the same rights as the other people doesn't come into it, even in council networks, in local papers in the country - I mean, the DRC does the metropolitan work, and they have only very limited hours too. Always you get the thing of somebody who is disabled is doing something like this - "Isn't that good?" - whereas if it had been a normal person doing it, well, that's par for the course.

In education - I mean, I went through university after my car accident, and I wasn't actually seen as anything different. I've travelled the world and I've been excluded from drinking in places throughout the world, but (indistinct) that. There just, I don't know - the community has to learn, has to be educated that the people with disabilities are not special, we don't have special rules, we are just part of the community. We have the same rights and the same obligations as everybody else, and people say to me, "What do you mean community education?" and I hark back to a report done in the mid-80s by the New South Wales Paraplegic Quadriplegic Association, which said, "Mid-30s, life expectancy of some with paraplegia, quadriplegia, was two years." In the mid-80s for a paraplegic it was 10 per cent less than the life expectancy of the normal person. For quads it's 15, 20 per cent. So that we're going to get more disabled people around, even allowing for the fact of the age thing. They're probably going to have more people wanting to get out and do things.

I've travelled the world and you see not that many disabled people out in the streets. I was in England - I was in London last year, England and London and Ireland, and the number of disabled people out in the streets was very minimal, and that's frightening. I would go to the galleries on the south bank, I'd go to the East End, and I'd go even into Trafalgar Square and Mayfair and those sort of places, and yet when I came back to Australia, having not seen any - or seen one or two people in a wheelchair in say the south bank of the Thames in London, which is a big gallery area - I went to the Italian showing in the Melbourne Museum here, and stumbled over five or six wheelchairs, people in wheelchairs, so they are out there, and people have to get used to it, that they are not special and they are not getting any special rights.

One of the very good things that is coming through the ACL, through one of their auspice organisations, is called Companion Card, which David can tell you more about, but the community has to be educated - the Companion Card, which is for a person with a disability who needs another person to get them into a sporting event, a cultural event, the pictures, things like that. If they need that person, they get that other person in for no charge, and if people are going to say, "This is favouritism to the disabled," it's not, and people have to learn that.

MRS OWENS: Could I just come back to your very interesting comments about comparing what's happening overseas and places you've visited compared with here. What do you think is the reason? Is it because people can't get into the West End or whatever, because of going on the Underground? Is it transport or is it attitudes - - -

MS McKENZIE: It's because many of the buildings are old and are difficult to access or - - -

MRS OWENS: Probably a combination.

MR EICKE: You give me a six-month grant and I'll travel to Europe and I'll tell you.

MS McKENZIE: Can we come with you? We might want to come too.

MR CRAIG: There was an interesting comment by a young woman who uses an electric wheelchair who went to do some postgraduate studies in - I think it was San Francisco, but certainly California, who, when she came back to Melbourne noticed quite significantly how she was reminded of having a disability in Melbourne that she didn't experience when she was away, and I think she largely attributes that to the effectiveness of the American Disabilities Act at forcing compliance, so that she was able to catch buses, go shopping, rent a flat, go to uni, and it was as if her disability disappeared - is the way she puts it. I think it reinforces this idea that disability is largely socially constructed. It's in the attitudes of the design and the environment people are trying to get around in.

If the services and the environments are much more friendly and afford people equal access of movement and freedom of movement and opportunity, a huge amount of the disability that has to be addressed with resources and funding disappears. It doesn't solve all the problem but it's a significant additional cost to the community that compliance hasn't been effectively addressed in the length of time that we've had to address it.

In the trends of new building sites - and you may have seen the press in the Sunday papers here, the Sunday Age, of the Federation Square project, which is a major icon in the city of Melbourne - - -

MRS OWENS: Yes, we did.

MR CRAIG: There are major issues there that just demonstrate that true compliance is furthest from the mind of architects, planners, builders and even governments who pay for it.

MRS OWENS: This is a reasonably recent building. We had a huge architectural competition. We had what were meant to be very good architects but somehow we still end up with a building or an area with flaws.

MR SMITH: And probably a brief to try to prevent skateboards.

MRS OWENS: That's why they've got all the rough - - -

MR CRAIG: The architect was interviewed on 3LO I think, some months back I heard him and he was quite chuffed about the extent to which they'd taken their efforts to exclude - you know, to make it a skateboard unfriendly environment. Of course in doing so - they spent money doing that, they've invested architectural effort and they appear to have spent very little of that on looking at the accessibility of the site, and the safety and the risk issues. It comes down to, I suppose, another comment we make in our submission about competition and economic effects. Unjustifiable hardship, as you say, is very easily the resort of a person who's been complained against - as a reason for not having to do something.

In fact, even the reports from both the minister and the project managers in the Federation Square project indicated that they do it bit by bit and money was an issue. I would argue that they would have trouble proving that in law, and it also fails to recognise that people with disabilities are part of a community, and a significant part of a community that spends money. Steve made reference to the Companion Card when we were pushing through this idea that in the act is a section, in section 8, that says a person shouldn't be disadvantaged in regards to requiring an assistant, an interpreter or a note-taker. We use that section of the act to argue that people who couldn't go out into the community without an assistant because of their disability are being discriminated against when they're asked to pay extra for their assistant to enter any event.

We've managed to develop, I suppose proactively, with this sector and with government, a scheme for Companion Card which is about to be launched by the state government in the next few months. But interestingly, in that process we were discouraged by HREOC in terms of the likelihood of getting that up and winning with that as a discrimination case. There was a case taken through the process of HREOC over the Sydney Olympics by a Melbourne-based young guy who wanted to go to the Olympics and see those. That was settled out of court again, so there's no sort of systemic impact of that decision. But interestingly enough, the transport standards have actually actively ignored that issue and require that each person travelling on transport will be required to pay for a ticket or pay a fare.

There are interesting issues; just that little example of that. Producers say, "You know, we're going to have to wear this cost." We say, "No, it will be built back into the ticket cost. We'll all pay a little bit extra so that everyone can have equal access." Some of those economic arguments, and even the fact that people now can be purchasing a predictable ticket - what it's going to cost and what the arrangements are for accessing it, whereas in the past that's been a very frustrating and a very humiliating experience for many people who have had to go and negotiate their barter - what the deal might be today, what concession can they get. They're just an example, I suppose, of how the arguments around competition and economic hardship are sometimes not weighed up against what's the additional benefit going to be in terms of users paying for use there.

MRS OWENS: Can I just come back to what you said about HREOC discouraging you from taking it as a discrimination case. Did they give you any reasons for that? I think what you've illustrated is that there are other ways to get your objectives met, and you've obviously been very effective with the Companion Card, but what did the HREOC say? Did they say you didn't have a case?

MR CRAIG: Didn't think the case would get up on the grounds of economic hardship. We were particularly also thinking about airline travel, and we know that airline travel arrangements in Australia - you know, there is currently a two-for-one arrangement you can get through Qantas and it's administered by an organisation called NICAN but it's only for the full economy fare. You can usually buy two tickets cheaper than that anyway on the discounts that are offered. We know that the variation of ticket pricing is quite significant. I think there was an article in the Australian some nine months ago that just showed that on the same flight for the same type of seat, people were quite incredibly different - - -

MRS OWENS: Completely different prices.

MR CRAIG: Yes, and we think there is, within that regime, no difficulty in accommodating that. When we talked about the airlines there was a sense of, "Oh, you won't get that one up. That would be too hard to get through, based on economic hardship or unjustifiable hardship." What concerns me is that if that's the place you go to for support to take up a case where we think the act offers some encouragement, you'd expect fairly proactive support. Now, I don't know whether it's because they're underresourced and overstretched, therefore there's some rationing of what's likely to get up and what isn't; I know that's certainly - if you're looking for advocacy support through that system, that tends to be I think an unfortunate feature, you know, when there is overdemand on the support.

MRS OWENS: Then there will be some choices made.

MR CRAIG: Some choices made about what's likely to get up and what isn't.

MS McKENZIE: But, in fact, would you say that since you went down the discussions road, rather than the complaint road - did the fact that you could say, "Look, irrespective of what the final outcome might be, there's this provision in the DDA that might assist us"? Did that help in negotiating?

MR CRAIG: Using that was very helpful and we actually were fortunate enough to get a supportive statement from a commissioner at HREOC and certainly very strong support from Di Sisely, the Equal Opportunity Commissioner in Victoria, for in fact she has chaired the working group, which involves industry, government and the community sector in working through the issues - the implementation issues of bringing that system into place. I think it highlights that sometimes you do have to do other approaches that involve community education and systemic advocacy.

As we pointed out in our submission, systemic advocacy is being reduced by governments, who are preferring to fund individual advocacy over systemic and are specifying that in contracts. The capacity to support systemic process is another tool for bringing about the kinds of change and using the legislation. We sought that and our act is probably fortunate that it has that little statement in there. I suspect it was in there more to do with note-taking and attendant caring in educational environments but it has been used - - -

MS McKENZIE: Not limited to that though, is it?

MR CRAIG: No, and we've found that it's probably unique in discrimination acts in having that particular reference. It's been particularly useful in this case. It certainly recognises that a person that can't go into the community without support has been discriminated against by having to wear that extra cost as governments tend to - but there's no funding to pay carers' entry costs and things like that. They pay salary maybe; most times it's a volunteer or a family member that's providing that support.

MRS OWENS: I'm just wondering whether this will get taken up now in the other states.

MR CRAIG: The scheme has been designed to be easily nationalised, although it's run through a state jurisdiction, and we're certainly encouraging other groups and other states to buy into it, because a lot of the organisations you deal with, like the

Australian Football League - AFL - a lot of the promoters and others have been sort of national in their focus, so they want a consistent approach across - - -

MR EICKE: We have been notified that some of the other states have been leaning on us through NICAN. I mean, if you go to a conference - I went to a conference last year. This little lady popped up and she said, "Exactly. What about it?" She wanted to know about it, so I just passed on the message to her via email that it was probably going to come up this year. She got it and she'll spread the word. That's it.

MS McKENZIE: That's good.

MR EICKE: There's an organisation called Disability Australia which Graham and I are members of. We sort of talked about that earlier - a few months ago. The other people in the other states didn't know what it was or what it was about, but it will get around and people will sort of say, "Can we have it here?"

MRS OWENS: You've set the precedent now.

MS McKENZIE: That's right.

MR SMITH: You mentioned an interest in what was happening overseas. As a member of the executive of Disability Australia, which is recognised by DPI as being the Australian accredited organisation, I've been to two different conferences - regional conferences - Asia-Pacific region - in Bangkok in the past year. One was on unemployment issues and a technical consultation on that, and it was disappointing to see that the ILO has statistics which indicate Australia has one of the lower percentages of people with disabilities actually working in the workforce. There are some structural reasons for that. One is that we're one of the few countries that has such a high safety net. Therefore, people with disabilities don't have to work, whereas in most of the other countries in the Asia-Pacific region the safety net is the local community and the family.

MS McKENZIE: But on the other hand, in Europe there's a fairly high safety net too.

MRS OWENS: Is that comparing us with Europe or comparing us with other Asian countries?

MR SMITH: It's comparing us within our region.

MR EICKE: Then again, in the national conference that we had in Melbourne in grand final week last year, we had a police officer who had been on a Churchill scholarship to go to study the way that the police force handles people with disabilities in Europe. He said he was out on patrol and he said, "What would you do if you had a mentally ill person there or a person with a disability out on section 8?" He said, "They wouldn't be here, they'd be locked up." I think in much of Europe there is still a culture of locking away or being ashamed of the person. I'm not sure how much of that is changing but this is what I'm still getting.

MR SMITH: The other point I wanted to make about my experience with delegates from the Asia-Pacific region is that in many of those other countries the self-help or national disability organisations are working with their governments to try and introduce disability rights legislation, rather than discrimination legislation. I suppose my personal perspective is that while I found the environment extremely challenging, and there would be lots of complaints in our system if the environment was challenging, I found that the social acceptance of me as a person with a disability in Thailand was totally different to the kind of social acceptance I get in Australia. I was not discriminated against as a person with a disability to anything like the same extent that I am - I get the feeling that I am in some areas of Australia. The social environment, to me, is quite different for a person with a disability, to here.

MRS OWENS: So accessibility is a problem, things like services and perhaps employment also, but not attitude?

MR SMITH: I would say attitude and employment are not problems to the same extent as they would be here, but physical accessibility - it just seems that things just get plonked where they get plonked and there's no consideration for - it was interesting that in Changmai there was an area of a good kilometre of footpath that had been put down with blind tactile tiles right down the middle of it, and six months later I was back to the same location and there was one of those pedestal-mounted telephone boxes mounted directly over the tactile tiles. People who are blind would know exactly what the result would be.

MS McKENZIE: I understand what you're telling me.

MR SMITH: And then 50 yards further on - or every lightpole had been put down right in the middle of the tactile tiles as well. Someone who was blind would have significant trouble navigating, but that is an infrastructure problem in Thailand. The attitudes to individuals I found quite different.

MRS OWENS: Maybe they were trying to help the people in wheelchairs, so that they wouldn't have problems with the tactile indicators.

MR SMITH: Half the poles and telephone boxes impede wheelchair access.

MRS OWENS: No, but maybe it was an indication you don't go along that bit; you go along another bit of the footpath. No, I don't think that was - I was just being flippant. I think we might have to come to a close. Are there any others comments you wanted to make? We've got your submission and there's heaps of issues in there. Lots of stuff in there. I think it was very clear.

MS McKENZIE: Are there other matters you want to raise?

MR SMITH: Just one tiny thing and that's the complaints mechanism or education, which we sort of touched on - monitoring compliance of educational standards. It took us over seven years to develop the educational standards and I don't think anybody on the task force that I was on - I think it would have taken us another two or three years to work out, on that task force, how to monitor compliance because there's total disagreement on that about what compliance would mean anyway. I think that is going to be something that is done elsewhere, not by a task force that is nominated by providers.

The complaints mechanism, which is the same standards as for the act, is a real problem in the education area, particularly the school area, because it immediately results in an adversarial situation. I think the way that parent advocates in particular have been working in schools - we're getting fewer and fewer of them, in Victoria anyway, because the ones who were trained back in the 80s no longer have school-aged children. But parent advocacy has always worked very hard to resolve problems within the school, and to try and develop a cooperative attitude. Immediately you start introducing complaints to an outside authority, it's very threatening and it results in social damage.

All the other things which immediately result in the possible - in the imagination at least it's in consequences for the child. So complaints mechanisms have not been used, in this state at least - or in most cases - until things have become untenable. It would be wonderful if some other way of resolving issues surrounding discrimination that was closer to the grassroots level could be developed. A complaints mechanism that is based in Canberra, or even a complaints mechanism that is based within the Equal Opportunity Commissioner of Victoria is one that discourages parents with young students in particular.

MRS OWENS: Thank you very much for that and thank you for coming. I think we really could have probably gone for another hour but we can't because we've got our next participant waiting, so thank you.

MR EICKE: Thank you very much.

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

MRS OWENS: We will now resume and the next participant this afternoon is Andrew Van Diesen. Hello, Andrew. For the transcript can you please give your name and the capacity in which you are appearing.

MR VAN DIESEN: Andrew Van Diesen and I am appearing on behalf of myself.

MRS OWENS: Good, thank you. Thank you for coming down from Bendigo on the train.

MR VAN DIESEN: No problem.

MRS OWENS: I will hand over to you and you can introduce your submission for us.

MR VAN DIESEN: Okay. I suppose I'll say that from what I've seen I basically concur with what has been said so far. However, I would personally prefer to take another tack to it, and that is to actually look at the DDA itself - whether it actually is effective and, I suppose, in this - two points. The fact that this is the Productivity Commission and this is a competition policy hearing is quite important because it denotes value - which I will speak about a bit later - and also I suppose, just looking at the DDA from this point of view, I would probably refer the commission to some of the work by Amartya Sen, in particular his *Development as Freedom* and just looking at the various freedoms that competition and even the markets provide.

Section 3B of the DDA indicates an objective of legislation is to ensure as far as practicable that persons with disabilities have the same rights to equality in law as the rest of the community. There I would just like to question whether it does in the light that it almost removes the legal aspects in the way that I had a complaint last year that got through to conciliation. Discrimination was proven. At that point it was pointed out to me that it would be more expedient for me and for HREOC to decide to actually barter away what I thought - with the discriminators to barter what was to me appropriate reparations.

In that case they actually removed my legal rights. I was also in that same protest told that maybe I should not go for high reparation or anything like that because the other party has legal representation. That also takes away my legal rights. My concern therefore is that it actually negates the legal rights by saying, "Here's another path we want to follow with you and, regardless, even if discrimination is proven, it's effectively not going to mean much more than maybe an apology and a handshake," whereas in that case it was a case of I was seeking employment and I was overlooked simply on the basis of disability and the financial cost to me for having been overlooked for that position might have only been $10,000 - as it was a part-time position - of income, but also later on down the track the opportunity of saying, "Yes, I've done this. I've proved that I can do this," so, yes, what legal rights then do I have, or is that - as I said before - as section 3B says, is this a practice or occurrence for the legislation?

I suppose part of it also - just in explanation I must say that I have got a - doing a masters degree in education at the moment. I've done my DipEd. I'm a qualified teacher, and I've probably been for about 200 interviews in the last 10 years and in a lot of those cases I've come into the interview and I've presented my credentials, as usual, but then there has often just been a way that the principals have been able to say, "We've got concerns in our head about your performance with the duty of care - of students in your care." Even though I present reports, et cetera, of my having coped with such circumstances at practical and even in some work situations, it is the old legitimate - for them to discount me, even though my academic credentials are more than outstanding.

It is legitimate for them to say that because we think this is a trait which people with disability have and probably everyone gets some expectation of the people as in what you're going to be like - what you're expectations for service and so on are, and almost a second standard simply because the DDA actually provides, especially with the standards and action plans as was discussed earlier by Disability Rights Victoria, that there's only a minimum understanding and, if anything, they only ever provide a minimum, and a lot of businesses, councils, et cetera, continually just look and say, "This is the minimum that we're supposed to provide," and usually that's just all they'll do - a minimum - but the act should be stating a maximum.

It's actually stating ways you can then get around it. I suppose to explain it a bit more: last week I got a call up from a reporter in the Sun. She had spoken to others and got my name in relation to travelling on the trains and the fact that being a wheelchair user, being put into - having to ride in the guard's van and I was asked what's that like and I said, "They also carry chooks, machinery, other livestock and goods, et cetera, in the guard's van." Whilst the piece that appeared in the Sun on Tuesday after I'd been spoken to was good in highlighting the issue, in a sense it sensationalised it in that it made it exceptional, I suppose, firstly, that people with disabilities actually do use the trains. My fear after that is how many people with disabilities or wheelchair users would look at this article and then say, "Okay. Is that how people in wheelchairs are treated here? Therefore that's something we must avoid."

There was nothing on the fact that I simply don't use trains because I'm disabled or because I'm in a wheelchair; I use them to get from point A to point B, for teaching work, for academic and professional research work, for various meetings and so on, in Melbourne. I also have family and friends in Melbourne. So, you know, it's highlighting - it's almost highlighting the disabled element in the commuter element. That’s a real big issue with the DDA. It defines "disability" under a medical term, thereby every person with similar medical conditions is regarded under those terms only.

It then turns around and defines "discrimination" under a social term, which is really - it’s not really looking at the issue, because the disability as such is not necessarily with the person, but with the society who defines that person. I suppose a good example is unjustifiable hardship. All of a sudden, if parties can claim unjustifiable hardship as the reason why certain practices, certain services. exist as they do, then maybe what - well, certainly there’s no understanding then of the original legal principle of what discrimination is, and therein comes into value.

The DDA simply removes the value of people with disabilities, and value in our society is most important. This is why I referred you to Amartya Sen’s work. Simply with - I mean, I don't mean exceptional value, that people with disabilities should be regarded as exceptions, but they should be regarded as equals. That's the problem that's coming down in the standards and so on. I've made a few suggestions at the end of my piece, for relevant remedies. The first one is the charter of rights, applicable to everyone without exception, and that will, I suppose, give it a legal face, as in, I suppose, equality.

After that, the second one - simply because we're still very much in a legal status where we have the DDA and we have, I suppose what you term "feeling out" of public views of people with disabilities and their rights, because I mean, at least we've gotten rid of a large number of the institutions and so on, that used to exist just simply to keep people with disabilities out of public focus.

As I said to you, the second one was the process of affirmative action. This is up for review, exactly the extent that that is needed - just sufficient, I suppose, to be able to equalise situations. The third part is that there is a need to shift the emphasis from being complaints-driven to a more self-regulatory one. Why should I have to rely on the disability discrimination law simply to uphold my consumer rights? Should not consumer law exist to protect consumers, all of them? Does the DDA then regard people with disabilities not as consumers?

The final thing - the final alternative I recommend is an interactive system of quality assurance support. Again, this is probably more just to bring community awareness more to the front. I've generally found that things like - particularly in schools, access and provision of ramps, and disabled toilets maybe, generally schools either lack the basic infrastructure, or they're almost the opposite, simply because they have had people with students with disabilities, and parents who have pushed these things in the past.

It's sort of becoming part of the culture that they have students with disabilities, rather than their need to comply, because there is a sharp difference in compliance and cultural acceptance simply. You notice this with wheelchair toilets - wheelchair-accessible toilets. I think that under the building regulations, I think the problem is there's two dimensions given that they can comply with, and more than anything a lot of builders - because half the time they're cutting costs - comply with only one of them, and that is much reduced in area, and you simply will not get a wheelchair in and around, in those areas. But then they turn around and say, "Yes, but we've complied with what we have to."

So, yes, partly it's a cultural thing, whereby simply more people with disabilities are now coming out into the streets and using things, and generally people will be okay with accepting you, and even to a degree will make access easier. But if they don't see people, if they don't have disabled users, they don't, and when they see the DDA compliance, as opposed to cultural acceptance, they see the DDA compliance, really, simply because they don't have any point of reference. Questions?

MS McKENZIE: So am I right, that really what you're saying is, the most important thing is the cultural acceptance - that in a way DDA compliance misses the point, and that that's a much more important thing?

MR VAN DIESEN: Well, I suppose we're working from the great problem in that DDA simply came in because, before which point in time it was not really an issue, because more often than not people with disabilities were not seen, and therefore did not have any needs that may need to be met. So the DDA came in to introduce that. The point that it really did miss is simply the equality, and by that it needs to probably express a simple human rights or charter for everyone, rather than just people with disabilities.

More often than not, these days, you often get more people - more businesses, more businessmen, more professional people, more academics starting to, I suppose, come out of the woodwork, express issues. They basically understand what the DDA is doing and what people with disabilities need, simply because they're actually able to express that they've either got relations or they know people with disabilities. For instance, the parents' lobby is quite substantial for the disability industry, and I suppose it's good, to an extent. However, we need to be mindful of it simply because it removes people's ability to talk for themselves and it removes our ability to even want to listen to people talking for themselves. If they've got someone else to whom they can talk, so be it.

MRS OWENS: Although in these hearings it has been largely people coming and talking for themselves. Sometimes with advocates - we did have a parent in here yesterday with a little girl - she is a 13-year-old - with cerebral palsy. But largely I think it hasn't been the parents as much as the individuals themselves, which has been terrific.

MR VAN DIESEN: All of the advocates that I've seen here today generally also have come in from the background that they actually do have family members with disabilities. So there's a bit coming in there too, and you've got to be mindful that - I suppose mindful of whom this discussion is for, who is to benefit. Certainly, yes, it's an interesting point because - just knowing some of the transport situations throughout the world. In France, for instance, they have low-floored trams everywhere, but they've actually gone through what is happening here now with the shop owners in Richmond complaining so much about - they want to take away all the parking spaces from in front of them because they have actually found in Paris that the parking spaces actually end up being a detriment to the businesses because it actually kept people from being able to come along there freely; they would have to walk around these cars.

Similarly, in London for instance, with the taxis, I don't think there is anywhere near the problems we have here with getting the accessible taxis simply because every taxi in London now is a wheelchair accessible thing. I suppose it needs to really be looked into, what all-round savings can be had by total compliance because I suppose partly, here, with accessibility issues, accessibility is not only an issue for people in wheelchairs, but people with prams have huge problems getting around town. It's areas like that where it has got to be actually - I suppose - rationalised for everyone's sake rather than just for people in wheelchairs.

MRS OWENS: I think we have covered the issues that we wish to cover. I'd like to thank you. You have given us some other perspectives that some others haven't.

MS McKENZIE: And some alternatives. It is really an interesting submission to have made to us. A lot of submissions have looked at how the DDA might be changed, but not so much stand-alone alternatives.

MRS OWENS: And the philosophical - - -

MS McKENZIE: The philosophical basis.

MRS OWENS: You've got some more philosophical questions in there, which I think are very interesting ones to contemplate. So thank you for that.

MS McKENZIE: Thank you very much indeed.

MR VAN DIESEN: Yes. No problems.

MS McKENZIE: We will break, and I think we will resume at quarter to.

(Luncheon adjournment)

MRS OWENS: This is very informal, so you can call us Cate and Helen. We will now resume. The next participant this afternoon is the Disability Discrimination Legal Service. Welcome. Could you each give your name and position with the Legal Service for the transcript.

MS CAMILLERI: Margaret Camilleri. I am the coordinator and legal education worker at the service.

MR BLARDO: My name is Placido Blardo. I am the case work solicitor of the service.

MRS OWENS: Thank you. Margaret, I think you said you wanted to make some introductory comments. I don't know whether Placido does as well, but I will hand over to you.

MS CAMILLERI: I just wanted to give an overview of basically what was in the submission about the funding of the service and the sort of work the service does. The service receives $159,000 from the Commonwealth government and we have just been told this financial year that we will be receiving approximately $16,500 from the state government which will be ongoing in our recurrent funding.

We approximately will give advice to 300 clients. The highest number or types of areas we assist in are employment, education and provision of services and facilities. Then, to a lesser degree, provision of goods and accommodation. They are the major issues, although we do certainly assist with matters in relation to transport, banking, finance and those sorts of things.

The service provides casework and legal assistance. That involves conciliation hearings and also through to the Federal Court. We also provide legal education to community groups, the government sector and also local government. With the time we have left we try and - - -

MRS OWENS: I was going to say, what do you do in your spare time?

MS CAMILLERI: That is generally an overview. The funding we have is administered through Victoria Legal Aid and we are one of 43 community legal centres in the state.

MS CAMILLERI: Thank you. Placido, do you want to add to that?

MR BLARDO: Not really. I will perhaps just highlight some of the items that I put on the written submission. Generally the submission is based on the experience I have as a casework solicitor. I have been in the position since August 1999. We do have state-wide coverage and a lot of issues come to us related to disabilities. Unfortunately we are not able to assist in some other disability issues, because our line of work and expertise is limited to disability discrimination only.

The first point I highlighted on the submission is about the definition of disability. I was a bit reluctant to do this because I recognised that the definition under the act is clearly very broad and very generous. It is probably safe to say it is a lot broader than compared with overseas jurisdictions. Then there is a decision of the court in Marsden way back in 2000 which, I think, amplified and extended the otherwise very broad definition that included addiction. I thought the commission should look into that because at the moment it is still quite unclear how addiction might actually constitute a disability, inasmuch as addiction might refer to substance.

I think right now we also see a lot of addiction to gambling, which is of a different nature. I really don't know how that would be looked at in terms of someone claiming protection under the act. I think I put on the submission that already in New South Wales they have qualified the opportunity to claim protection in relation to addiction in as far as employment complaints are concerned. I think it will be really good to look at the definition, particularly in relation to disability, and see how the act could provide better protection to those who may have an addiction one way or another.

MRS OWENS: Has it ever been tested for gambling?

MR BLARDO: I don't think so.

MS CAMILLERI: Not that I know of.

MRS OWENS: That is an interesting question.

MR BLARDO: I think so, because gambling is recognised as an addiction, but it is not classified as substance abuse. It is a different genus by itself.

MS McKENZIE: We looked at the whole problem of gambling in our gambling report a couple of years ago. I don't know whether we talked about it as being an addiction, but there are certainly people who are classified as problem gamblers. I don't know what the answer is but we will look at that.

MS CAMILLERI: And due to that addiction they can lose their homes, all their assets and so on, so it is not something they have a lot of control over.

MR BLARDO: I think the definition includes disorder and malfunction and perhaps that is one way of including that type of addiction; but to save the hassle of going to court and getting the court to define what might be included, perhaps something more specific can be proposed. Perhaps it is best for parliament to deliberate on that issue rather than a case-by-case basis whereby an applicant might be deterred by costs in testing whether the definition includes that particular condition.

MS McKENZIE: In New South Wales they have qualified.

MR BLARDO: Yes.

MS McKENZIE: It is an interesting point.

MRS OWENS: You also raised behaviour as another area in terms of - - -

MR BLARDO: Yes, I did, and I have had a look at the submission of another sister centre interstate and pretty much we are saying the same thing. I think we would like to see a more open definition in such a way that a person who might be displaying certain types of behaviour might be able to prove that the behaviour itself constitutes a disability without having to prove it is a direct result of a disability.

I do recognise the problems that may arise there, but I guess it is also one area the commission should look into because in my view the decision in the Purvis and Minns case puts a lot of burden on the complainant already. Otherwise I reiterate the submission made by the other centres.

MS McKENZIE: There are a number of problems in the Purvis case. One had to do with whether the behaviour constituted a disability or could somehow be regarded as part of the disability. The other had to do with the comparator, which is another matter.

MR BLARDO: I do agree there and I would say I agree with the decision in regard to the lack of compactor. It is really the notion of manifestation of behaviour that I am having a problem with. I think even the court somehow in its deliberation has indicated that had the case been argued (indistinct) somehow, the result would have been different.

MS McKENZIE: Yes.

MR BLARDO: The second point I raised was in relation to the definition of assistance animal. This is something that came to us I think about four months before we first met with the commissioners. We had a client who had some problems and to deal with those problems she needed this pet. She lives on her own. She is single and had some issues in relation to mental health. Her doctor said she keeps a pet by way of alleviating the challenges posed by her illness. It so happened that her landlord did not want her to keep a pet.

It was my view that under the current qualifications to offer assistance animal, her pet might not qualify as one, because I think there is a requirement that the animal be trained. I do understand the policy reasons why such training might be required, especially in the case of a guide dog entering a public premises. In her case I thought she was a recipient of a service and her assistance animal would be confined pretty much in her private premises. I thought if the definition could be looked at to somehow contemplate those situations, then she could somehow lodge a complaint and the act could protect her.

MS McKENZIE: Would you think of that instance you raised as being one limited to accommodation or would you want to broaden it out?

MR BLARDO: I would like to think it would not be limited to accommodation. Also I do consider that in terms of the person accessing other services that might involve other members of the public, then there are overriding public safety measures that I think the requirement for training is addressing. I would like to think that somehow that qualification in the definition does apply, other than accommodation.

MRS OWENS: Well, there is access to restaurants with an animal or access to public transport or aeroplanes. Of course in other societies all three of those are allowed, but not here.

MR BLARDO: The third point I have actually relates to a case where we have not lodged a complaint yet, because our client is overseas in relation to an ongoing conference about deaf issues; but I believe this complaint may have gone to the commission some time ago. There may have been some resolution by conciliation which is protected by confidentiality. I don't know exactly what is happening, but the issue we are raising is the fact that a lot of movies that come in DVD formats may not have captions for the hearing impaired.

We have taken some samples and we know if they are produced overseas we are trying to get around the problem of being able to make those companies based overseas responsible, because I think if they are supplying something to Australia the Trade Practices Act somehow should require them to make sure it is suitable for the purposes it is meant for. If it is a movie that can be watched by a deaf person then it should have options for captions; otherwise it will not be completely accessible to a deaf person.

The problem I have identified is the fact that it would seem that the local distributor might not have the capability to actually add captions in those products. I have since learned that to actually add captions to a movie in DVD format it may mean using some space that somehow will affect the general content of the movie. I don't want to sound as if I am indicating I am an expert insofar as the technical specifications of DVDs but I think most DVDs, apart from the regular movie, have other programs like interviews - production interviews - and stuff like that. I think if the movie does not come with captions then somehow the space available in the disk might be affected such that if a product comes to Australia and the local distributor wanted to comply with the act and make that product accessible, it might actually be physically and contractually possible for him to do so - for the person to do - physically because this might not allow it - the program might not allow it - and secondly, it might not be in the contract because I would say that the manufacturer and producer would put some value in relation to the other features in that program.

MS McKENZIE: I wonder whether there might be some copyright problem as well. I don't know.

MR BLARDO: That's true as well. I think that copyright is a major issue. I would say that the distributor would not be in a position to actually alter anything unless it is with the authority of the producer. It just brings it back to who bears the cost - if they allow this. So what we have here is a manufacturer that we're trying to make liable, and them saying, "Look, we want to do it, but we can't." And we're back to square one where we have a product which is not accessible to a deaf person.

MS McKENZIE: That would involve giving the DDA an extraterritorial operation which has some interesting problems in itself.

MR BLARDO: I would say so. I confess that I don't have a concrete idea of how to go about that, because of the limitation on the territorial jurisdiction of Australia. But I believe there must be some way that it can be done. With the ongoing free trade negotiation between the US and Australia - the US being the major supplier of these products - I don't know the capacity of the commission to somehow - but I thought it was worthwhile looking at.

MS McKENZIE: A lot of this stuff - not all, obviously - but some of this stuff will have been produced in the States. What's the position in the States? My recollection is that there is some requirement in the States concerning accessible formats for at least certain material, and some requirements to lodge electronic copies in the Library of Congress.

MR BLARDO: My understanding under the US jurisdiction is that they are required to provide captions for any movies produced and distributed locally, but once it is marketed overseas, I think they don't have to comply with that.

MRS OWENS: My son imports lots of DVDs - too many DVDs; there seems to be one arriving per day - but some of his movies have captions on them and he gets them from the United States.

MR BLARDO: Yes.

MRS OWENS: I suppose you could always say that in terms of selling it to the Australian market, that all DVDs have to have captions, and then the incentive would be for the distributor to find access suppliers than can provide caption movies, whether they come locally or come from America or wherever.

MS McKENZIE: You could certainly catch importers who distribute, and you could catch sellers here and you could catch wholesalers here. It's just a problem about catching manufacturers who don't distribute or sell here, but who only operate overseas.

MR BLARDO: But the problem I see in relation to limiting the action to, let's say, the local agent or the distributor, is the fact that they might be able to rely on a defence of, "We just cannot do it." Because captioning is easily done at the source, it's probably cheapest that way.

MS McKENZIE: And it would wreck the product, or it would damage it in some way. You're right, you've got your copyright problem as well, which - - -

MS CAMILLERI: It's what you were saying before, about the distributors actually sourcing products with those captions on them for distribution.

MRS OWENS: So they wouldn't be required to try and do it themselves; they would look for the appropriate source.

MS CAMILLERI: Yes.

MRS OWENS: And if there was a manufacturer here - if we had that sort of regulation in Australia the local manufacturers, if they were producing for export market, would probably also want to be supplying to the local market and they'd probably make their products accessible, too. They wouldn't be able to export to the States, for example, because of the requirements there.

MS CAMILLERI: Of course, I would have thought there'd be similar restrictions in other areas, I guess, of wholesalers sourcing material - whether it be foods, goods or toys or whatever that have certain standards - that they have to meet in terms of then its distribution within Australia. So I wouldn't see that this would be dissimilar.

MRS OWENS: I suppose there is a trade-off to other consumers that don't want captioned products; whether the price of the product goes up because of the captioning. I don't know whether it makes any difference to the price whatsoever, but I suppose some might argue that if the price was to go up as a result of having to have all products captioned, that they are going to be disadvantaged. So it's a trade-off of the rights of one group to get access to captioned material, against the rights of another group to buy their products at the cheapest possible price.

MS CAMILLERI: Yes, I don't know what the cost is, but certainly when we talked about similar things being done in Australia I don't think it's particularly prohibitive, but I guess it's making those sorts of decisions. I guess there are restrictions on other things because of their concern to a group within the community. You might have particular - I don't know - allergies or something around particular food that's imported, for example. I don't know if there are those sorts of trade-offs. I guess it's a matter of how accessible and how serious we are about making things accessible to the whole community.

MR BLARDO: The fourth point that I raise is in relation to the Migration Act. I believe that my counterpart in Hobart, Judith Blades - I'm reading the minutes - has raised this as well.

MS McKENZIE: Many people have raised the Migration Act.

MR BLARDO: Yes. I just have a particular interest in this because I used to practise in migration as well. There are just two points there: I thought the fact was that the Migration Act of 1958 supersedes in effect the Disability Discrimination Act. There are policy reasons why that is the case. I'm not endorsing those policy reasons. I do understand there are. So I don't endorse the policy reasons but I think in at least two cases that exemption must be relaxed. I gave an example whereby if the person claiming protection - it's actually not the visa applicant, but rather the person who is already an Australian resident or citizen - it seems to me that there is no logic at all why the act should apply comprehensively to someone who is not in any way applying for a visa; whereas if you look at the reasons why medical health check might be required of these applicants - we do understand why that must be done, but if the person seeking protection is already a citizen and a resident, what will be the danger - if you can call it danger - that the act would hope to prevent? It doesn't seem to me logical to apply the exemption.

MS McKENZIE: So if a person with a disability here, who is a resident or citizen, makes some application for the entry of someone without a disability from overseas, then the act should not prevent that.

MR BLARDO: The second point that I raise - the second situation I think where the exemption should be relaxed, is in relation to Australia being the only country that detains asylum seekers. It's my view that what they call visa processing centres are simply a prison environment. I would venture to say that if a person has a mental illness, or may have developed a mental illness as a result of being confined in that prison environment, then there should be that capability to challenge the fact that maintaining that person in that same environment constitutes indirect discrimination. Sadly, that could not be maintained because the act provides a very comprehensive exemption under the act. I think that argument is more consistent with the purposes of the Human Rights and Equal Opportunity Commission Act.

MS McKENZIE: Yes. I understand those two arguments.

MR BLARDO: The fifth point I raise - and it's something quite uniform in many submissions - is in relation to cost consequences. Although there have been a number of decisions where both the Federal Court and the Federal Magistrates Court - since the time that the Human Rights and Equal Opportunity Commission lost the hearing function - there have been those cases whereby costs orders have not been awarded against unsuccessful applicants. It still remains to be determined. I ventured to put in what I thought would be at least four cases whereby the court should not award costs orders against unsuccessful applicants.

MS McKENZIE: People in other submissions have gone further and just said that they should only make costs orders where the case is manifestly vexatious or frivolous; otherwise not.

MR BLARDO: Yes.

MS McKENZIE: So you've been very circumspect in what you've said.

MRS OWENS: But it's very useful for us to have this alternative approach.

MS McKENZIE: Yes, it is.

MRS OWENS: And I thought your criteria that you used was very sensible, so we'll look at that, and we'll also look at this other view - this stronger view that Cate mentioned of vexatious - - -

MR BLARDO: I don't mean to actually in any way affect the general discretion of the court. I think what I'm just proposing are some specific cases whereby the applicant would be reassured in that "I don't have to worry about cost consequences." If I could give an example of this, because we had a client who I thought had a very good case in terms of redefining the exemption of the Australian Defence Forces.

We had a client who applied to be a soldier in the Australian Army and she indicated that some 10 or 12 years ago she had a condition that somehow affected her sleeping patterns. That was 10 or 12 years ago and she was just being candid about her application and somehow the recruitment office looked at that as an indication that she might have some underlying psychological condition that would make her unfit for duties as a member of the ADF.

I thought that with the exemption under the act perhaps we could look at that as the Commonwealth imputing a disability. We thought maybe we could run an argument that insofar as the exemption of the ADF, it should not include an imputed disability - because I am trying to draw a reasoning why there is an exemption. If a person has a disability, then there are demands required of the position of being a soldier, but if they're just imputing a disability, then I guess the exemption should be limited. So we thought we would do that, but then pretty much early on in the application our client reconsidered, because I could not give her guarantee that we would be successful.

MRS OWENS: Was she worried about the costs?

MR BLARDO: Yes. She was worried that there would be costs and it was my role to alert her that there might be cost consequences. I would like to think that in that case the court would perhaps exercise the discretion in her favour, that it would not be awarded, but I could not advise the client that that would be the case. So she withdrew the application. I think it was one of those cases where you see a genuine issue of law that really only the courts could decide. And why should we penalise someone, even with the prospect of costs orders, if something is so unclear.

MS CAMILLERI: And in that case too, and other cases like that, they are genuine sort of public interest matters I think, and they are usually against government departments and those organisations can afford to bear any cost consequences out of going to the Federal Court. When you are faced with opponents like that you are not going to take that risk, not when you are on a disability pension or not even if you are earning a wage. It's just unrealistic to think that people will go that far and take a risk, despite the fact that there is a good chance that they might be successful, with that guarantee they are not going to take that risk, and so they are certainly not going to bring out those issues I guess, of discrimination, that could assist more people than just themselves.

MR BLARDO: My last two points actually I would say do not really relate to the act itself but pretty much in relation to the function of the Human Rights and Equal Opportunity Commission and I was saying that you have these provisions that define victimisation, inciting a person to commit discriminatory conduct, discrimination in advertising, failure to provide the data required by the commission, failure to provide information or produce documents, or giving false or misleading information. And they all look all right but it has just surprised me that since 1993 - - -

MRS OWENS: No-one prosecutes.

MR BLARDO: There has never been anyone who has been made answerable to this. I'm pretty sure that with so many cases that have gone to the commission that there will have been a number of breaches. I don't know whether these sections still serve the function that they are meant to, or perhaps they could be read in such a way that we will give more life to them rather than just them being an offence that seems to be toothless at all.

MRS OWENS: Why do you think those provisions haven't been used? Is it lack of awareness that they are there, or is it again too hard?

MR BLARDO: I would like to be corrected in this view. I think it's just that prosecuting these offences is perhaps not high on the agenda of the commission. I think it's not just priority work for them.

MRS OWENS: Do you think it might have something to do with the resources of the commission?

MR BLARDO: That's one reason as well, and I think because it's an offence by itself, that it will require the intervention of a police agency. And in here I remember having discussions with one of the senior investigators of the commission and she indicated to me that the Federal Police would not seriously take these complaints to a level that they normally take some other cases. So there is that lack of, I think, interest, but I think that that somehow undermines the fact that these are very serious offences, I believe, and the fact that there has been no-one made answerable, to me is something that - - -

MRS OWENS: They are offences because that conduct can potentially undermine the whole act.

MR BLARDO: I think so.

MRS OWENS: So it's more really a question that they ought to be followed through and prosecuted, if that's appropriate. You don't want to turn the jurisdiction into something like a court, but they are there because if that conduct continues to occur the whole scheme of the act wouldn't work.

MR BLARDO: That's all I have to say, madam.

MRS OWENS: Thank you.

MS McKENZIE: Thank you very much.

MR BLARDO: Thank you.

MRS OWENS: Can I just go back? In your submission, and I think just at the outset, you said that you had a lot of clients but you've only been able to take on a limited number of cases - I think you said in the submission 229 clients, 59 cases. Now, is that because all the rest of them wouldn't have come in under the DDA or was it because you just can't take on all the people that come through the door and you have to prioritise?

MR BLARDO: It's a question of resources, really. We do have a penchant for cases that have strong public interest, but I do not really take that into account all the time because I'm aware that we are meant to provide a legal service and if we turn away clients simply because their case does not involve public interest we would really be turning away so many people, and we don't want that. But pretty much in terms of representing them either at the tribunal or at the court, we tend to be selective in terms of whether there is that likelihood of success, whether the case has a strong public interest. It's just purely a question of resources. We just could not simply provide that service to everyone.

MS CAMILLERI: It's just trying to balance what we have and how much we can do with it, and certainly public interest cases will assist more than that particular complainant. But certainly, as Placido said, we don't like to turn people away but in certain situations we do. But more often we will always try and refer them to another organisation so that they are given assistance.

MRS OWENS: So they go somewhere else and hopefully something will happen for those people.

MS CAMILLERI: Yes.

MRS OWENS: You mentioned, just at the beginning, about this additional money you are now going to be getting from the state government, $16,500 a year for recurrent purposes. What does $16,500 buy you?

MS CAMILLERI: At the moment we are looking at - our lease expires at the end of January, so we are looking for alternative accommodation. If we want to stay in the CBD that will go towards our rent, essentially, so it won't mean a lot in terms of increased services to the community. Obviously we need to look at other alternative accommodation; we are looking at a whole range of things. But I've just put the draft budget together and it's looking at basically most of that money going into rental or just keeping the service afloat. It doesn't mean a lot. It certainly doesn't mean one full-time worker and it would mean perhaps a worker for - if we were to sort of use it for worker time it would mean maybe one or two days a week.

MRS OWENS: You are probably grateful to have it because it's better than nothing but it's not a Tatts Lotto win.

MS CAMILLERI: No. And for us the centre has worked quite hard to try and get the state to contribute because we are now working quite a lot within the state jurisdiction as well. So in one sense it is positive in that this is the first time the state has contributed money in that way, for recurrent funding, so hopefully it will mean that over the years they will contribute more and more to the centre.

MRS OWENS: How do you decide whether you are going to use the Commonwealth jurisdiction versus the state jurisdiction? What's the criteria that you observe?

MR BLARDO: It has always been a difficult question for me, and I say that because in terms of substance I could not really tell clients that this law is better than this other law. But there are cases where I recommend to clients that we take it under the federal act, and there are cases where I pretty much alert the clients in relation to - "Well, this if this is not conciliated and you would want to take it further then this is the way you go." And most of them like the prospect of being able to deal with a tribunal rather than a court.

MRS OWENS: And the tribunal is pretty much a no-cost jurisdiction.

MR BLARDO: Yes, and that's one thing that really convinced them of that because they know that they don't have the prospect that they would be paying legal costs. Also, in terms of time frame - and I don't think this is anything to do with the legislation but just in terms of the fact that the Human Rights Equal and Opportunity Commission is based in Sydney, and the state commission is based in Melbourne, so in terms of being able to table conciliation conferences, and travelling arrangements, it's more convenient to have matters at the state commission.

But in terms of substance, really I would not say that the local commission is in any way an inferior legislation; I would not say that. But there are, I think, a couple of points that I advise clients to take, when they have to take complaints under the Disability Discrimination Act, and the first one relates to where the subject matter of the complaint is provision of service and the respondent is a local government, like a council. I think that the tribunal has a couple of decisions whereby it was said that to qualify a supervision of service, that service must be something provided to the individual rather than to the community at large.

An example of that would be roads and footpaths. So whenever there is such a case I tend to use the Commonwealth act because I'm not aware of a similar decision made under a DDA, and I thought that the chances of the complaint not being declined would be a lot greater. The second point is in relation to whether the respondent is a Commonwealth body, then I prefer that complaints be dealt with under the Commonwealth act, especially so in relation to implementation matters where the applicant may be subject to federal awards.

MS McKENZIE: And there are some that you might not actually be able to take under the state act in any case, like some of the telecommunications authorities arguably might - the DDA might be the only place you could complain.

MR BLARDO: Yes, and in terms of substance, the last point is in relation to going back to the definition of disability. I think in terms of illness my view right now is that a condition like flu might be better covered under the Disability Discrimination Act because the federal act includes "An organism capable of causing an illness." So I tend to think that conditions like that are better taken under the Commonwealth act rather than the state act. But otherwise, in all respects, I think that the state act is a very useful jurisdiction and very user friendly.

MS McKENZIE: Can I ask this? If it were to be decided that HREOC could initiate complaints in cases where a great public interest was involved or some systemic matter or where, for some other reason, individual complainants couldn't lodge one, some of the submissions have raised the question of some conflict of roles then, if you are acting as conciliator and complainer, if you like. Have you got any comment to make on that?

MR BLARDO: I didn't get the question, madam.

MS McKENZIE: Some submissions have raised a possibility that HREOC might be able to initiate complaints. Now, you, I think, in your submissions, have mentioned HREOC's role as a conductor of inquiries but some submissions have actually raised the possibility of HREOC itself being able to initiate complaints. Some other submissions have said that this might be a problem because of HREOC's role as a conciliator. Have you got any comments to make on those submissions?

MR BLARDO: I understand the logic of the concern, if the commission were to take that dual role. I wouldn't agree that it's actually a great conflict because in a number of ways the commission does take on a specific stand in relation to a complaint, like in relation to the exercise of its threat and intervention function. But if the commission is initiating a complaint, and because the nature of the process is investigatory and conciliatory, I do not see, really, a great disadvantage to the respondent if the commission will have been the person to have initiated the complaint because the conciliation process is pretty much limited to finding a resolution to the complaint.

In 99 per cent of the cases there are no admissions of liability, so I tend to think that in terms of any disadvantage to the parties, whether it is the complainant or the respondent, I don't think there will be any apart from that notion, that being the same person who initiated the complaint and is sort of conducting the conciliation is the same. I'd like to think that the commission would, whenever it takes that role, be guided by the fact that it has a special position in the community and is a statutory body, such that it will be different to someone assuming a dual role just for the sake of doing it.

MRS OWENS: Yes. You also mention in your submission itself that - well, you refer to having a comprehensive and rigorous investigation by HREOC in reviewing a complaint, and it seemed to imply that their investigative powers at the moment are not sufficient - you know, that there's some problems with the investigations at the moment. Is that what you were trying to infer?

MR BLARDO: To be honest, I'm not exactly sure whether it is a case of the current investigative function requiring some more or granting the commission more powers, but it may be just a case of perhaps the present concern conducting the investigation. It might just be a file management issue. I raise that because I'd like to think of the commission - and this is true for both state and federal commission - that it should not just be a venue where the complainant and respondent will exchange correspondence. I just think that we should highlight the fact it is an investigative commission.

It should draw out a lot of information that we are acting on behalf of complainants, would not be in a position to disclose, and it's just that if that is done comprehensively at that stage, then even the prospect of going to court is something that we could address easily because if you're armed with some information in the first place, it gives us as advisers a better perspective in relation to how the case might proceed if litigated. It would somehow give us a better option to enable the client to have a better informed decision, but pretty much - I've seen a lot of cases whereby the commission will write a letter to the respondent eliciting a reply, and in most cases respondents would be quite protective of whatever information they may have that perhaps according to their legal advisers may not be suitable or may not be of great help to their case, and I'm just thinking that the commission should really probe into that, because we have no way of knowing what they would be and, as I said, it might just be a question of the style of the investigator or perhaps a file management issue.

MS McKENZIE: But might that probing not lengthen the process before the commission? Would that be a problem?

MR BLARDO: I wouldn't say it would be a problem. I think that the fact that it's meant to be an investigative commission - then it should not just merely rely on information provided to it, but it should actively seek out information that would in some way show indications that (indistinct) has actually taken place. The commission right now do not make any determination but somehow at that stage, so we need to see a lot of information that somehow will indicate what really may have happened.

MRS OWENS: If that case went on to the court, would that information be provided to the court as well?

MR BLARDO: Well, hopefully it would be, and I think it's our task as well to ensure that that is provided, but I'm just saying if we leave it at that stage, then we have to go through the process of discovery, of a more complicated process of seeking them out, and the advantage of having them available at the outset is - you know, we could somehow advise the client that this is not discrimination, perhaps you should look at it differently, and somehow that would stop this person engaging in a process that may not be to his or her benefit after all.

MS McKENZIE: Having that information - would that help conciliation, do you think, as well?

MR BLARDO: Definitely. I think that's the first thing that we require. Conciliation is somehow sometimes looked at as one way of getting rid of the complainant, but, armed with that information, I think it gives us a lot of bargaining power.

MRS OWENS: Thank you both very much. Is there anything else that we haven't raised with you that we should have?

MR BLARDO: I just want to ask whether the inquiry will have some way of affecting the Senate inquiry in relation to the fact that there's a proposal to remove the intervention function of the commission, because we vehemently oppose that - - -

MRS OWENS: Sorry, I didn't - which power of the commission?

MR BLARDO: To intervene.

MRS OWENS: The intervening?

MR BLARDO: Yes. I don't know whether it is something that the commission - - -

MS McKENZIE: We've got a problem, and that is that our terms of reference only permit us to inquire into the DDA. They don't actually give us a mandate at large to inquire into the HREOC Act, and while we feel we can look generally at the complaints process because it's pretty hard to divorce it from the DDA in that way, we get a bit more worried when we start to look at things which are really general and which, if we want to look at them properly, we would have wanted in our terms of reference the Racial Discrimination Act and the Sex Discrimination Act, so you can actually look at them in the broad, because that intervention power relates to everything.

I know the complaints powers relate to everything, but we've taken the view that you pretty much can't divorce the prohibitions in the DDA from the remedies. It's pretty much impossible. But having said that, we are going to list issues at the end which were raised in the submissions and which we regard as important, so it may be that we could mention that issue, given that you're raising it so vividly in that list. So you're saying you strongly oppose taking away the - - -

MR BLARDO: We do, I think it's a view shared by a lot of advocates and I think that the record is there to see, that in so many submissions made by the commission, most of them will have contradicted the position taken by the government, especially in cases that have recently attracted a lot of publicity, and it's just that to actually create a screening process for that function to be able to exercise is something that I think undermines the independence and the very nature of the commission. We would want to see the commission being able to freely exercise the power to apply to intervene in a particular case.

MRS OWENS: Okay. Thank you for that. We'll now break for afternoon tea.

MRS OWENS: The next participant this afternoon is Dr Harry New. Welcome, and thank you for arriving early. Thank you also for your submission, which covers a range of issues related to taxis and access to premises and heritage buildings. For the transcript if you can repeat your name and the capacity in which you're appearing and we'll also be able to see whether we can pick up your voice.

DR NEW: Dr Harry New, and I am appearing to provide a submission to the Productivity Commission on behalf of my wife and I.

MRS OWENS: Thank you. I understand, Harry, that you would like to make a few points related to your submission.

DR NEW: Yes. I have prepared some notes, which may to a large extent cover what I have already put in my submission to you, but this more or less just clarifies it or summarises it and puts it into perspective, so I will proceed with that. My wife and I have been very involved in campaigning for appropriate access with dignity for disabled people to various venues available to the public - reception centres, cinema complexes, restaurants, theatres - as well as equality in regard to the availability of efficient and effective taxi services for the disabled.

During the past 13 years we have found that there has generally been an appalling lack of conformity with regard to the Australian Building Code and the Disability Discrimination Act by operators and owners of facilities or services, as well as an apparent lack of awareness by local and state government departments. The first point I will make is resistance from councils and government departments to the extent that sometimes one might feel paranoid and think that there could be some collusion with the providers of the services.

Examples where difficulties have occurred have included our personal involvement with the Princess Theatre in 1990, the Jam Factory in 1996, the Windsor Hotel in 98, Regent's restaurant in 2001, the Classic Cinema in 2002, and a very welcome difference and responsible attitude in regard to the cinema complex by the Bayside council in 2002. Max's restaurant at Southgate had steps in this very new centre and they proved to be resistant to changing the access, but did not respond publicly after we took them to the Equal Opportunity Commission in 1998. They did respond appropriately after we took them to the Equal Opportunity Commission.

Even the state-owned Arts Centre has deficiencies, particularly in regard to the Playhouse Theatre, and could be improved upon. Complaints were also followed by a sympathetic response and a promise to improve things in the future, and nothing is happening yet in regards to the Arts - to the Playhouse Theatre. What happens there is that we are compelled to sit in one of the boxes and the boxes do restrict your vision of the performance.

MRS OWENS: Because they are over right on the side, aren't they?

DR NEW: You're high up and you don't always see what's happening, like the audience - they get a full view of the stage. At some plays we have missed out on something very important which other people can see.

MS McKENZIE: Yes.

DR NEW: Point 2. Strong resistance remains evident in the case of the Events Warehouse on Southwharf Road, Southbank, though it may be that some moves are being made in a positive direction, albeit slowly. Have not heard yet about any development at Shed 9, having approached the operator about effecting a ramp entrance on Southwharf Road, so that disabled people and those in wheelchairs would have the same equal dignity in gaining access. Although operated and managed by a private concern this reception venue is actually owned by the state government.

The Melbourne City Council failed to respond to a copy of a letter we had written to the management, whose response has been lacking. Permission would be required for the Heritage Council - the owners, presumably the government - and the Melbourne City Council, and generally the response gave the impression that it may be very difficult to carry out such work. All these people would have to be approached and it worked out whether they could put up a ramp.

Point 3: every now and then we pass a restaurant with steps to get in notwithstanding that it has obviously been extensively refurbished. We wonder how the council could allow the development to take place even though it is an obvious breach of the Disability Discrimination Act. Point 4: I know of some pre-1991 reception centres that are quite large and well attended by many people but, because they were built before the Disability Discrimination Act came into being, there seems to be nothing that can be done, either under this act or the Australian Building Code, as it is an existing structure. However, they are popular, large in size, but the provision for access is lacking and usually there is no provision for access to disabled toilets for wheelchair-bound people. I understand that the act does not allow for any action to be taken in regard to such venues, or at least this is our impression.

Point 5: for as long as we can all remember there has never been a proper taxi service for disabled people whereby they have access with dignity and equality, free of discrimination. Waiting for a taxi to arrive for up to an hour is still not uncommon for disabled people in wheelchairs. This is despite the continuing complaints to the Victorian Taxi Directorate and the minister of transport. His replies to letters are always along the same lines: self-congratulatory about the improvements to the taxi service and continuing efforts to improve it further for disabled people, usually involving increasing the number of available taxis. They keep missing the point, that it is the taxi drivers who are failing to comply. It is almost impossible to obtain the services of pre-booking for regular and permanent times whereby the taxi driver is fairly reliable, although I have met up with a couple in my time who have tried to be responsive to the needs of the disabled. One example is a driver who brought us today.

Recommendations. It could be made compulsory in regard to access issues for premises for the service of the public, such as theatres, cinemas, reception centres and restaurants, and generally places of entertainment, to provide access with dignity for disabled people in wheelchairs, and it should be possible to be made conditional for all existing permits. Another condition - except for small establishments where hardship may be involved there should be some requirement for access to be available.

So far as taxis are concerned the problem seems to be more with the drivers. Generally they choose for themselves if and when to answer calls for wheelchair pick-ups. Education, I do not think, would be enough, and the licence to drive the multi-purpose/M50 taxis should be linked to a renewal system based on performance; that is, the number of wheelchair pick-ups they have made. It is noted however that in some countries - at least in the UK - I have been given to understand that all taxis are available to take wheelchairs, so that one just calls a taxi and whatever arrives will be required to take the passenger, able-bodied or wheelchair-bound. They could learn from that. Overall the emphasis should be on increasing the awareness of operators, owners of relevant premises or services, as well as governments, both local and state, of their responsibilities under the Disability Discrimination Act. That completes my submission.

MRS OWENS: Thank you. I think you also made the point in your submission that we have already read that sometimes it has been useful just to have had the threat of the act.

DR NEW: That's right. That's when we're dealing with a responsive authority, but a lot of the time they are very resistant. The Classic Cinema, for instance - they blocked off access to the restaurant adjoining the cinema. Access was there, available, and they went and blocked it off because they wanted to use that corner where the doorway was - an accessible doorway. They wanted to block that off so that they could use their tables and chairs to serve their own wine and coffee from their own bar. We fought against that and they - - -

MRS OWENS: Did you win on that one?

DR NEW: Yes, we did. We were here - with Cate McKenzie, I believe.

MS McKENZIE: Yes, you won before me, but then I think you went to mediation. That's my recollection. Is that right?

DR NEW: Well, the mediation ended up with the operator of the cinema, together with lessor of the complex - the owner of the restaurant, or the operator of the restaurant - all contributing towards having the cost of a separate entrance a few feet away from the previous entrance - maybe a couple of metres - and making a new doorway there, which was level and involved lowering the floor. They each contributed $20,000 to the cost of that - that's the owner of the restaurant, or the operator of the restaurant, the lessor and the operator of the cinema complex.

MS McKENZIE: And now everybody can use that entrance?

DR NEW: Yes. Furthermore, the operator of the cinema complex spent $100,000 in legal costs in fighting us, and even threatened to get us to pay towards the costs claim, they claiming that because it was a frivolous claim, they were going to get us to pay some much in costs - or to pay their costs. Well, fortunately it didn't come to that. The commission found in favour of us in that regard.

MRS OWENS: When you actually go to that cinema complex, you can't still get access to all of them, can you, because some of them are upstairs? Or is there a lift up?

DR NEW: There's a lift up, and there's a ramp access, so that you can get to the back of the cinema. No, we've got access to all of the cinemas, but there's a lift that takes wheelchairs. I think so.

MS McKENZIE: But for the most part, the other organisations that had inaccessible reception venues, have they generally done more to try to respond to your issues?

DR NEW: Well, I remember there's one - Tudor Court, for instance, in Caulfield - Kooyong Road there - what they've done is, they've made a temporary wooden ramp where you can get in at the back entrance to one of their reception halls. But we thought, well, in this day and age, if you're going to put a temporary wooden ramp down which has to be put down, and when you want to leave you have to tell them that you're going and they've got to put down the ramp, or when you're coming they've got to be notified that there's someone coming in a wheelchair, then they put the ramp down - well, surely they can - after all their refurbishments they've done there, surely they could be made to put down a permanent ramp.

But the Windsor Hotel has got a step up the front; why should they - after spending about $30 million refurbishing that place, why can't they put down a ramp there, get rid of the step? Chairs like this, and most motorised chairs, can't get up the step.

MRS OWENS: Well, once you get in there, you've still got the problem of - if you want to go to the toilet.

DR NEW: Yes. Well, when we wanted to go to the toilet, they took us to the - they've got a guest room, so we went to the guest room and - they showed us where the guest room was. My wife took me there, and we were supposed to be able to get into the toilet there, but the toilet was inaccessible; we just couldn't get in.

MRS OWENS: It was just a normal bathroom, one of the normal Windsor bathrooms?

DR NEW: Just a normal bathroom, yes. In order to get in - well, yes, that was just an impossibility. We got over it in my case, because I carry a drainage bag on my leg, and it had to be emptied out into a receptacle; then my wife would have to go to the toilet and empty it out in there. Well, that's not a very - that's not access with dignity.

MRS OWENS: No, and it's not equivalent in any way to the access that a person without that disability would have.

DR NEW: Yes, and they spent a fortune fixing that place up, but because it's heritage listed, they were told that they couldn't build access into the toilets.

MRS OWENS: But they were able to build a Hard Rock Cafe on the corner.

DR NEW: Yes, that sort of thing.

MRS OWENS: I suppose its priority for them - - -

DR NEW: What's profitable. Like with the passage, the reason why they closed off that access was to - for them to be able to operate their cafe bar in the foyer, so that they could make their little venture there more profitable. That's what they said.

MRS OWENS: What about the taxi booking issue? You said you've written to the Taxi Directorate, but they don't really address the issue. You've also written to the Honourable Peter Batchelor on 29 May. I know you put your submission in to us - it came on 8 July, but I was optimistically going to ask you whether you'd had a response yet.

DR NEW: Yes, we did get a response.

MRS OWENS: Which said what?

DR NEW: Applauding himself, applauding the efforts that are being made by the Ministry of Transport, "Look what we've done. We've got all these taxis at the facilities, all these taxis on the road, and you're going to get even more. Things have improved over the years." But, really, people still have to wait for lengthy periods of time.

MS McKENZIE: Much longer than a person without a disability would have to wait.

DR NEW: That's right. You have to wait for an hour sometimes - well, even for half an hour. An able-bodied person could get a taxi in less than half an hour, usually.

MS McKENZIE: And that's a regular thing, that kind of waiting period?

DR NEW: That happens fairly regularly.

MRS OWENS: You said in your submission you have a regular booking, and that you can't even get that regular booking.

MS McKENZIE: And it's still like that.

DR NEW: Yes. But if you get a good driver who's responsive and understanding and empathic, he will do his utmost to arrive on allotted days. But they're not always available; not every taxi driver is like that. Most of them want to get on with the job and get some more bookings, and to go and pick up a wheelchair takes a bit more time.

MRS OWENS: Even with your good driver, if that driver is out at Tullamarine at the time you need to travel somewhere, you're not going to get that person.

DR NEW: But he knows beforehand. This taxi driver we've got is a particularly good one. If we could get him right - but when he's on holidays or when he has days off and he can't do it, or he's out of the way, he can't make it that day, then we have to rely on somebody else. When the allotted time comes, 8.30 in the morning, say, three days a week, the taxi hadn't arrived, so we ring up the Black Cabs and ask them what's happened, "We haven't got a taxi yet," and he says, "Oh, it's on its way. It'll be there soon." "Well, how soon?" "Well, he's out in West Melbourne at the moment so he might be half an hour."

MS McKENZIE: He's got to get to St Kilda East.

DR NEW: Yes. Sometimes we have waited. They've said, "Oh, he's five minutes away."

MS McKENZIE: Is that by plane or ship, or just by car?

DR NEW: Yes, "five minutes away" so my wife would say, "Are you sure it's five minutes or is it going to be half an hour?" "No, no, only five minutes." So we waited, and nothing happened. We waited half an hour, still nothing happened. So my wife took me - we've got a van, a little van. She had to go out of her way to take me to work that day. So we had someone at home, and told us that the taxi did turn up eventually, about quarter past 9, so it took three-quarters of an hour; so that was three-quarters of an hour late. So it wasn't five minutes.

MRS OWENS: We thought we might - well, some of our staff tested the system this week, on Monday, to go from the other end of town down here with a whole lot of equipment we needed to bring down, and decided we'd order one of these cabs and see what happened. You may not be surprised to know that nothing happened. They waited for half an hour and the taxi didn't turn up. So we were quite sympathetic to your cause. Now, you've got a solution to that, which is to link the licensing of the drivers in some way to the number of disabled pick-ups.

DR NEW: That's right.

MRS OWENS: Would that act as a deterrent then for those drivers that drive the multi-purpose cabs to actually drive those cabs, and just go back to regular cabs? Could that have a negative impact?

DR NEW: Well, to get a regular licence, I don't know what it costs now. The cost of a taxi licence, I think, is something like in the vicinity of $200,000 or $300,000 and to get a licence for one of those multi-purpose taxis, which carry wheelchairs, would be something like 60,000.

MRS OWENS: But in some cases the licence holder is the person who drives the cab; in other cases they use baillee drivers, and we heard in our hearings - I think it was in Sydney - that it's not so much the people that own the licences that are the problem, it's the people that they get driving their cabs - - -

DR NEW: That's right.

MRS OWENS: - - - where there's not going to be that commitment to - and they're not necessarily going to worry about the licence either.

DR NEW: Don't they have licences, these drivers - the other drivers?

MS McKENZIE: I think they have licences - they must presumably have licences to drive taxis. I assume they have more than just the simple licence to drive. The concern of the taxi industry that was mentioned to us in their submissions was that if these drivers get more regulated, they'll just simply quit driving the special-purpose taxis and just go back to driving ordinary taxis, so it will make it even harder to provide drivers for the special-purpose taxis that there are.

DR NEW: So how do you get around it?

MS McKENZIE: We would very much like to know.

MRS OWENS: Well, maybe it's a matter of making the taxi companies - the licence holders responsible in some way. If they're driving for Silver Top, make the big boys responsible. It's a series of small businesses working under that banner, but maybe there has to be responsibility right at the top.

DR NEW: I have spoken to taxi drivers about it, and they've pointed out, well, it's up to - I think it was the Equal Opportunity Commission when it seems to be pointed out that it's the drivers who just aren't responding appropriately. It's a difficult one to resolve. I don't know. You've got to tackle it from all ends, I suppose; get the taxi drivers to - compel them to - on the grounds of - not relicensing them unless they perform, and the taxi companies have to be - it's more increasing awareness.

MS McKENZIE: And maybe some disciplinary measures as well. I know there are some taxi companies where - I think, because they can now track vehicles, they know where vehicles are, because that's how they're given their jobs, with the automatic radio. It would be much harder with smaller companies, but at least bigger ones might be able to - if a person with a special purpose taxi - if there was a call for a special purpose taxi and one was clearly in the area and had not taken some other job and still didn't take that job, then it may be that they could then in effect ban that person from using their radio calling facilities for a period. There are, I would have thought, some disciplinary actions that taxi companies might adopt as far as that is concerned.

DR NEW: After all, they have got that licence at a very cheap price, $60,000 instead of $300,000. After all, they are misusing the service.

MS McKENZIE: Harry, you have made a complaint to the Victorian Equal

Opportunity Commission. Have you made complaints under the DDA as well?

DR NEW: About the taxi services?

MS McKENZIE: Yes, under the Disability Discrimination Act.

DR NEW: I am not sure. I don't think we did. We tried to do so, if I recollect accurately, and the respondent claimed that our claim was misconceived and it was up to the drivers to respond - in this case it was the central booking service that was in operation. The central booking service could not be responsible if the individual drivers aren't performing and are not responding to the calls. They could put the calls out on the radio or on their computers and it is up to the drivers to respond.

MS McKENZIE: It is very hard for someone who finds a service is not working for them to work out the right person to complain about.

DR NEW: I complained to the directorate, to the Minister for Transport, to the government and you keep getting the same story all the time.

MS McKENZIE: The trouble is, how would you know what driver didn't take your booking? You wouldn't know because he didn't turn up. It is impossible.

MRS OWENS: So it really does come back to the responsibility of the cab company.

DR NEW: If they don't turn up, but what about the ones that turn up late. Fancy sending a driver who is out in West Melbourne to come to East St Kilda and expect him to be there within 15 minutes at 8.30 in the morning.

MRS OWENS: There is another dilemma with this that if you have standards which dictate that the response times should be that X number of calls need to be done within 10 or 15 minutes - whatever - the problem is that that also is going to provide an incentive for the drivers not to take that particular booking because they won't want to be penalised under that standard, so they will just say, "I am not going to go for that one because I won't make it." That just makes it worse. I am ever hopeful because we look at what has happened with the cabs and we seem to be getting newer cars on the roads in Victoria now and we have the cab drivers wearing uniforms. There have been some general improvements. Maybe this is the next one to tick off. It is not just here.

DR NEW: Why not try to aim for something like they have in the UK where they have the taxis there always - the large cabs - which can take the wheelchairs. All you do is just call a taxi.

MRS OWENS: And whichever one comes can take you.

DR NEW: Yes. They don't have to know you are in a wheelchair.

MRS OWENS: You mentioned before when you were talking about the Classic Cinema, where in the end there was a shared responsibility for making adjustments in a restaurant and it was a building owner; it was the operator of the cinema and the operator of the restaurant. But it does raise the general question that if it requires some alterations to a building - or when you were talking before about the wharfs, that venue which is owned by the state government - who should bear that responsibility for those costs? It is an interesting question because the state government owns that facility. Should it be the state government?

DR NEW: They are leasing it out for the purpose of using it as a reception centre. You would think they would have taken that responsibility.

MS McKENZIE: Sometimes there is a whole chain. You have a head owner who leases to someone else. Then they sublease smaller areas to other people. You have a whole chain of people to deal with.

DR NEW: And the state government developing these sheds or leasing them off. They are very expensively done at a huge cost. You have to go along this rickety wharf to get to the entrance. What they have done with sheds 7 and 8 was to surface the wharf so that you got a smooth ride on the wharf and they have also put some wooden ramps to overcome the steps. Shed 9, the access for the general public is on South Wharf Road by steps and for disabled people it would be along the wharf along that very rocky ride. So even if they did surface that wharf with asphalt, or whatever, to make it a smoother ride, you would have a back entrance for disabled people and the able-bodied people are going to go in at the front. Why shouldn't the disabled people go in where the able-bodied people access?

MS McKENZIE: That is not the same kind of access.

DR NEW: No. Coming to the point about the Classic Cinema, they did at some cost then - shared costs - make that access available, but there is strong resistance to do anything; hence the $100,000 legal bill they were up for themselves trying to resist doing anything.

MRS OWENS: I think with the Events Warehouse people, at least they seem to have responded in a reasonably positive way. They have brought in disability consultants and at least responded to your letters.

DR NEW: Yes.

MRS OWENS: It looks like Wilson Parking is moving along, too, albeit this is happening slowly. You shouldn't have to rely on you going along and complaining about these things. It should be build into these places. When they are renovating them it should be built in, shouldn't it?

DR NEW: Yes.

MRS OWENS: And they shouldn't be able to be leased out until they comply with some standard or the Building Code or whatever.

DR NEW: The councils are at fault here. They issue these permits for redevelopment but the people don't abide by them. They take the permits handed out but are irresponsible in not providing the facilities - either accessible toilets or the access. There is a lot of strong resistance from councils, but Bayside Council was very responsive. When we pointed out to them that their toilet facilities were inaccessible and one of the cinemas there we could not access at all, because there were steps involved and the one that I could get in, I would have to sit at the very front row, after our complaint to the council they conceded that the Dendy complex were not doing things according to the permit, or the permit that was issued was inappropriate. They did come to the party, they did respond to our approach to the council. The Glen Eira Council did not respond that way in regard to the Classic Cinema.

There was a permit there and the permit stated with a diagram that that door had to be kept open, but they did not enforce it. So it shows the strong resistance of some of the councils. Why don't they respond?

MRS OWENS: It's interesting that there was a demonstration a week or so against the Glen Eira Council and the footpaths and the right of access around the municipality. You didn't participate in that, did you?

DR NEW: No. I missed out on that one.

MRS OWENS: I think the leader of that was an 86-year-old gentleman who said he'd never been involved in a demonstration before.

DR NEW: I didn't demonstrate but, yes, Glen Eira Council has got a lot to answer for. There was an article in one of the local newspapers saying that the council was going to make access to businesses in the council area, to make them all to be accessible, make access an issue, but nothing's happened there. What they say is probably only a vote-catching exercise, but they're not really genuine in their performance.

MRS OWENS: It's a wonder they've got a disability action plan under the Disability Discrimination Act. We might find out.

MS McKENZIE: Harry, can I ask you a question on a totally different point. You're a consultant psychiatrist.

DR NEW: Yes.

MS McKENZIE: We've had some submissions from organisations and people with psychiatric disabilities, about discrimination, particularly in employment, and raising matters such as the level of awareness among the community in general and employers in particular about psychiatric disability and what those with it can and cannot do. Do you have any comments to make about that subject?

DR NEW: I suppose it depends on how disturbed the person might be, if they have an emotional psychiatric disturbance, what they can do with what - what they think they're capable of doing and what they're actually capable of doing might be two different things, but let's say that they do have the capacity, that they do have the skills. A lot of them are lacking in motivation and reliability, but let's say that they do have that capacity. There's always the fear of anyone who has a psychiatric problem. People are afraid of people who - because they're different. They imagine that they might become violent or do something nasty.

MS McKENZIE: When in fact that's not going to be the case in all and probably most cases.

DR NEW: No, not at all.

MS McKENZIE: Yes, exactly.

DR NEW: The majority of people with a psychiatric disturbance - they're not all suffering from paranoid schizophrenia. They might be well controlled while stabilised with medication or with treatment. Yes, I think it would be an issue with people who are emotionally challenged or psychiatrically challenged.

MS McKENZIE: And other matters have been raised with us, such as insurance. There are difficulties which have led to some negotiations with insurers by the Mental Health Council.

DR NEW: Yes.

MRS OWENS: I think we've covered all the issues that we wished to with you, and I'd really like to thank you very much for coming along and talking about a lot of the venues that I go to myself and now start to see through different eyes.

MS McKENZIE: Both your written and oral submissions are very helpful.

MRS OWENS: Very helpful, and the taxi issue is also one that will continue to occupy our minds, and we'll see what we can come up with on that issue.
So thank you very much. Is there anything else that you wanted to raise with us that we haven't asked you about?

DR NEW: There are other problems of discrimination in a way. For instance, the physically disabled people - if they wish to go somewhere for respite, that is sorely lacking in the community. We end up having younger people - fairly young people having to be put into nursing homes, and that's a sorry state of affairs. We have people who have been made permanently resident in nursing homes because they've got MS and with advanced disability, so that's another one.

MRS OWENS: There's a whole lot of these sort of issues that people are bringing to our attention, some of which don't fit that comfortably into our terms of reference, but because they're such important issues we've decided that we're going to acknowledge these issues in our report and say to the government, "By the way, here are a number of other important issues, and this is what we think you need to be thinking about in these areas." So I'm really happy when people like you raise these issues. In your own situation with your wife away, have you had problems getting support while your wife is overseas?

DR NEW: No, I've been able to get a period of respite in the Bethlehem Hospital, Bethlehem Health Care, but we're made to feel that we're very lucky to have got in for this length of time, for a period of seven weeks, and the initial reaction is one of shock and horror - "But we can't do that" - and we put a bit of pressure on, and my wife threatened that she'll just leave me there in the foyer and leave it up to them to put me somewhere.

MRS OWENS: I was going to say, she couldn't leave you on the doorstep because you probably couldn't get up onto the doorstep.

DR NEW: No, she'd leave me inside the foyer and just walk out.

MRS OWENS: That would have been an interesting test case.

DR NEW: Yes, I think they'll just end up putting me in a nursing home, which would be worse. Well, I'd like to thank the commission for hearing me out.

MRS OWENS: Thank you for coming.

MS McKENZIE: Thank you very much, Harry. Thank you for coming.

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

MRS OWENS: The next participant this afternoon is the Australian Education Union. Welcome, and thank you for your submission, which I think is largely covering school education. Could you each give your name and your position with the union, for the transcript.

MR MARTIN: Roy Martin, the federal research officer with the Australian Education Union.

MS DAVIS: My name is Catherine Davis. I am the federal women's officer with the Australian Education Union.

MRS OWENS: Thank you. And Roy, I think it was, you said you'd like to make some opening comments.

MR MARTIN: Yes.

MRS OWENS: But Catherine, you are welcome to say whatever you'd like to as well.

MR MARTIN: I'd just like to begin by saying that this is one of the more important issues, from the point of view of our members, that whenever we get the members together and see what issues emerge students with disabilities is one of the issues that most regularly occurs and on which there is a lot of angst and a lot of difficulties and problems around. I'd also like to emphasise that I think the reason for that angst is frustration that is caused by wanting to do the best thing for all of the students. But the staff are put in the situation where they feel they must choose between the best interests of the student with the disabilities, the other students and their own health and wellbeing. And this causes considerable stress and difficulty in terms of where it goes.

In our submission we have outlined some of the apparent discrepancies between the definition or instance of disabilities in the community at large and in schools. The number of students in schools identified as having some disabilities is roughly around the 3 per cent to 5 per cent mark and we believe that the evidence suggests that the real incidence is probably between 12 and 20 per cent. So one of the first and most difficult issues is that a number of the students who should be receiving some assistance in the schools are in fact not even identified as needing the assistance in the first place.

The disabilities that are particularly overlooked are those connected with learning difficulties, with attention deficit hyperactive disorder, behavioural disorders and some of the ones like foetal alcohol syndrome and significant medical conditions, which are generally not included.

MRS OWENS: Can I just ask this? Chronic fatigue syndrome, would you add that into that list as well?

MR MARTIN: Yes. We support an expanded and more flexible and individualised approach, based on the identified needs of students in an educational setting. The current system tends to ascertain or categorise students and they have to be put into one of usually three or so classes, and particularly around the margins that's fairly arbitrary and can make quite a substantial difference to the level of assistance they receive. And so we would prefer a system that is more flexible and more negotiable and so on.

The current inadequacy or difficulties are around resourcing, and that's the most fundamental problem which underlines most of the other problems and prevents their solution. There is a need for, in particular, increased teacher assistance support - and I will deal with that in a little bit more detail in a moment - smaller class sizes and greater time release for teachers to prepare the programs for professional development in the disability area, and those kinds of things.

A lot of our members feel that commitments are made and the governments purport to espouse ideals for those with disabilities but don't make adequate provision of the extra resources necessary to achieve them, and this is hypocritical and unfortunately that's a perceived reality by a number of teachers.

The area that's most contentious - and I'm sure you would have found this in other submissions - is the inclusion or mainstreaming of those students. I'd have to say that I think the AEU understands and supports the principles behind inclusion and we believe that the extent to which it can be achieved is substantial but is highly dependent upon the level of resourcing that's provided to go with it. We do also believe that there are some circumstances where alternative arrangements and alternative settings at the appropriate situation can be made.

I would also comment that very often the emphasis is on inclusion, in terms of being in a particular building or a particular room, when often inclusions should also be based on programs and the nature of curriculum and the nature of teaching. They are very often simply sitting in a room where the necessary alternative materials and those kinds of things are not provided, and that is not really inclusion. So inclusion must include all of the areas.

I'd have to express some disappointment with the Disability Discrimination standards. When we wrote the original submission we were able to complain about the huge length of time it has taken to prepare them. I have to say, on my reading of them, that they don't really answer the fundamental questions that we hoped they would resolve, which go to things such as the actual locus of decision making in the public education system, and the extent to which the system rather than the individual institution must make the provision. That still left it, in my view, quite ambivalent in the standards as they exist.

Parents generally approach the school, they don’t go to the Education Department in the middle of town, and it’s the school that has to respond. But in a public education system the capacity to alter the resourcing often lies outside of the school, in a central bureaucracy. And the way that these two interact is extremely complex and often leaves schools and individual teachers, what we would call "the meat in the sandwich" in terms of the way that the decisions are made.

Just in terms of training and professional development, I’d have to say that professional development, in general, across all areas to do with teaching, is generally woefully inadequate and we regularly make submissions to that effect. And professional development in relation to students with disabilities is no exception to that general woefulness. What we would like to see, and feel is necessary, is that teachers are given some introduction, in their initial teacher training, to the teaching of students with disabilities, some understanding of the approaches that they can then later build on in response to particular situations. So some generic courses around the range of disabilities and the way that you might approach them.

There then needs to be both general PD, in terms of keeping up to date with things but there also needs to be a system of specific professional development in relation to when students with particular disabilities come into the classroom there needs to be some system to see whether the teacher has or has not got the necessary competencies in that particular situation and some system to ensure that they get it.

In terms of allied staff, or in some places these are called school support officers or teacher assistants, they are fundamentally important and play a magnificent role in terms of teaching and coping with students with disabilities. We’d emphasise their poor work conditions; the lack of training opportunities that they get and the need for more of them, for them to be more specialised and for that specialisation to be more recognised. Some of the saddest stories are teacher assistants who go out of their way, in their own time, to learn about how to assist a particular student in a particular circumstance and then because of the vagaries of their employment conditions they will find themselves doing something totally different the following year, like stamping library books or something like that. There is just a total lack of recognising the high levels of skills and the specific levels of skills that they need and of then putting them in situations where they can use those skills to the maximum.

MRS OWENS: Are they covered by your union?

MR MARTIN: We cover them in some states and territories. It's ongoing. And I could spend a lot of time explaining the vagaries of it but we do have coverage in a number of states.

MRS OWENS: In Victoria?

MR MARTIN: In some states it's joint coverage with other unions and in some states it's sole coverage.

MRS OWENS: What about in Victoria? Is it sole coverage for you or joint coverage?

MR MARTIN: No, I think in Victoria it's joint coverage. Then just finally I'd like to touch on the issue of non-government schools, which you were talking about before we sat down. We don't want the issue to become an issue or a fight between public and private. Frankly, we would have rather kept to that but - - -

MRS OWENS: You've actually got quite a few common issues, really.

MR MARTIN: Yes. I would say that the issues are very, very similar across the two and the situation is generally very, very similar, although in proportional terms there are considerably more in the public system than in the non-government system. I would just like to set on record that we do not accept the funding submissions that have been put in, in particular by the NCEC, and the way that they present the material. They have some difficulties in terms of the way that the money is allocated and the way that the AGSRC, which is their funding mechanism, operates.

I have a paper here by Dr Ian Morgan in the ACT that actually shows the Catholic system in the ACT is over-funded for its students with disabilities. I think probably it's best to say that the funding mechanisms do not address the situation adequately and if I could just give an example: basically non-government schools are funded on a proportion of average government school recurrent costs, which is AGSRC. If state governments were to have a major funding splurge - as a result of your inquiry, for instance - in regard to students with disabilities, the effect of that would be to raise the amount of money the Commonwealth provides to all students in non-government schools, regardless of whether they had disabilities or not.

So the funding for disabilities is incorporated into an average which is then given to every student. Now, in terms I think particularly of the Catholic system, there is an argument that they should be recouping that block of money. I can appreciate that in terms of very small schools, because of the vague nature and the fact that they don't get quantum, they are in a somewhat different situation. But the point to make is that the money is in the system but it is not being delivered to the students with disabilities in - - -

MRS OWENS: So basically the way it works, according to what you say, is that the independent schools receive from the Commonwealth a proportion of funds and that proportion is calculated from a total in which money for disabled students is included?

MR MARTIN: Yes.

MRS OWENS: So in effect the money that the non-government schools receive from the Commonwealth is a proportion of that money. So already there's an allowance made for - - -

MR MARTIN: Yes, and that would depend to some extent on the proportion of the average costs they were getting. Certainly, as I say, given the comparatively low incidence of students with disabilities, there is a view - and there are some calculations being done in the ACT which suggest that in fact they're funded at a higher rate than some of the government systems; but I say that in a context where individual schools may in fact not be receiving the money.

MRS OWENS: But the issues that you'd have in common, one would be this issue about being able to carry funding with you if you move from school to school. Is that right? One of the things that the non-government schools have said is that if you move from one system to the other, the funding allocated to you, a student with a disability, should be able to go with you.

MR MARTIN: That would lead, in the current circumstance to a fair degree of double dipping, because that money is already included in the average cost.

MRS OWENS: Is it not also included for government schools as well? If what you're telling me is right, isn't it that there's sort of a bucket of funds which includes both students with disabilities and students without and all that happens is the state schools get one percentage and the non-government schools get another, a lesser percentage, from the Commonwealth. Is that right?

MR MARTIN: No.

MS McKENZIE: The state schools get it from the government.

MRS OWENS: As well, yes.

MS McKENZIE: A state government project.

MR MARTIN: The money that goes into the government school is used as the base. There is no other figure. Then they work the average from that.

MRS OWENS: All right. But what's not clear to me is, you really need to look at the whole funding picture and look at what the independent schools are getting just through their general funding from the Commonwealth, then add onto that the add-on, the additional support that they get through the Commonwealth funding, and then compare that with what the government schools are getting from the state government general budget and then add on the additional support, then have a look at the whole funding picture, which sounds like a bit of a mess. What's not clear to me - I mean, what the independent schools are saying is that, for example, if you get into a secondary school and you're in a government school you get a range of additional support from 4000 up to just over 30,000, depending on the level of the child; whereas in the independent mainstream schools, it's something like - it averages 680 per capita.

MS McKENZIE: Far less.

MRS OWENS: But what you're saying is then that base money that they get from the Commonwealth is going to actually have a bit more in it because it's based on your average.

MR MARTIN: Yes.

MRS OWENS: There's an interesting exercise to do, which is to put the jigsaw puzzle together and see where it all ends up.

MS McKENZIE: Would you still say though that the funding for students with disabilities at government schools is not enough?

MR MARTIN: At government schools? I'd say there isn't enough funding for students with disabilities. In some individual instances it may be adequate. The problem sometimes is more funding for more students and, as I say, on the margins; so I guess what I'm arguing is not necessarily that you need an overall percentage increase but you actually need to examine where it's adequate and where it's a shortfall, but overall there is a shortfall.

MRS OWENS: One of the other things that the independent schools have pointed out to us is that when the standards are introduced, that might put pressure on schools to provide a greater standard of service which means that it may be necessary to have more resources to fulfil the requirements of the standards, so not only would you be talking about more money in specific cases - the argument that you're just putting at the moment - but it also means possibly more resources overall.

MR MARTIN: Could I just go back before I answer that to the previous one about the average costs? I think you have to be careful about average costs. In some cases there are economies of scale, in particular at public schools, which would make averages inappropriate in terms of the number of people who were in a school. And of course it's highly dependent on the way they classify the disabilities.

MRS OWENS: The other issue is, you said that the money question - it was not so much that you thought there was necessarily more dollars needed overall but that there's specific needs for some students in some areas.

MR MARTIN: Yes.

MRS OWENS: What I was saying was when the education standards come in, that might put the pressure on schools to increase the services provided to the students to meet those standards, which is going to - that has a resource implication.

MR MARTIN: The state and territory governments were very concerned the other way: that, in fact because in effect the resources of the government are fairly limitless in one sense, the issue of reasonable adjustment and hardship would fall more heavily on state government systems than it would on non-government systems. That's still in one sense - because it's not clear how the standards will actually work in practice because they don't resolve the basic questions of, if you like, right of entry; then it's far from clear as to how that will work out. It may well be that non-government schools can argue unreasonable hardship more easily than can the public system, the government system.

MRS OWENS: That might be the case because the independent schools might be seen as individual schools arguing a case, because they don't have that overarching government system.

MS McKENZIE: They're not part of the government.

MRS OWENS: Whereas for the government schools, they're part of the Victorian education system, for example, so it would be very hard for those schools as a whole, any individual school, to run an unjustifiable hardship case, because there's access to state government funds through the education budget. That might be the way it goes.

MR MARTIN: Yes, that's the argument that I'm putting, yes.

MRS OWENS: Sorry, we interrupted you.

MR MARTIN: No, I've actually finished that.

MRS OWENS: Okay. Well, we've run through some of the issues as we've been going, but that funding issue is a really interesting one. We've had some case studies from the independent schools as well, looking at some of the financial implications. Of course the small schools - we're talking about more hardship than possibly the big independent schools.

MR MARTIN: I would be very unhappy, I have to say, if the concentration is on the small independent schools that actually deal with a fairly small number of students with disabilities. I accept it's an issue, but the huge majority of students with disabilities are in the public system and I believe that some attention should be given to them and their needs and their situation.

MS McKENZIE: Absolutely.

MRS OWENS: Well, the reason I'm focusing on it is because just about everywhere we've gone the independent schools have come along and spoken to us, so they've been extremely well organised but we have not been hearing from individual government schools or from school systems. I think you're really the first group that's come and talked about these issues. That's why I'm very pleased you're here because we need to balance our discussions with you and I'd really like at some stage for some of the departments to talk to us as well. They may not even be aware that we're doing this inquiry. I don't know. But they certainly haven't been beating down the door to come and tell us their views, say on the education standards, which I think is a shame because they need to put that argument to us about unjustifiable hardship and their concerns about that.

MR MARTIN: I don't know whether you caught up with the MCEETYA meeting in Perth, the minister's meeting a week or two ago.

MRS OWENS: We know a little bit about that.

MR MARTIN: There was considerable dissent from most of the states with the exception of ACT and Tasmania from memory. Their major concerns were the cost implications for government schools and I mean basically the argument was over a proposition that the Commonwealth be prepared to meet the additional costs, whatever they are. The Commonwealth was unwilling to meet the additional costs whatever they are. It argue they were nothing but it wasn't prepared to meet them if they were more than nothing. I have to say that the states' and territories' costs analysis varied widely.

MRS OWENS: Yes, there was a huge differential, wasn't there?

MR MARTIN: Huge differential.

MS McKENZIE: Yes.

MR MARTIN: Which may not be entirely unreasonable, because each state and territory has a considerable different history in terms of the way that it has integrated students. Certainly, Victoria and South Australia are two states I know that got into it very early, back in the 60s and 70s. New South Wales and Queensland have tended to take the specialised facility line more and have applied that for a much longer period of time. So the implications for one state may well be very different to those for another state. I'm not really qualified to actually give you details of each of those, but one shouldn't assume that they all ought to be the same.

MRS OWENS: No, I wouldn't assume that, but there's probably a bit of that - the difference between the states and where they are as of now, but also probably a degree of arbitrariness in terms of how you calculate those costs.

MR MARTIN: I think there was a degree of difference in interpretation in the meeting of the standards which, as I say, having read the standards, I could well understand because I actually think they're quite contradictory in parts, which is the nature of these things, and it becomes a lawyer's paradise, and I don't believe that the standards go any way towards clarifying the areas of major contention. I think that's going to be a great - - -

MS McKENZIE: So do you think - I mean, would you say that the standards ought not to be there? Would you go so far as that?

MR MARTIN: We were very enthusiastic about the standards initially. We have been pushing very much for the standards, mainly because, as I say, we believe at the moment that it's individual teachers and schools that are having to resolve these issues, and our view is that the Education Department normally take the line of least resistance. So if the school doesn't kick up a fuss or make some kind of noise, the department will let it happen, and this places our members in a particularly difficult situation because often the only way they're going to get extra money is by engaging in what may appear to be somewhat discriminatory activities, and that makes it very difficult for them. If they don't do anything, the department will just let the situation exist.

MRS OWENS: What do you think about the standards' inclusion of unjustifiable hardship post-enrolment? In the act itself, there's provision for unjustifiable hardship defence pre-enrolment, but in the standard, it's been extended to post-enrolment as well. Do you think that was the appropriate way to go?

MR MARTIN: Well, I guess the key issue for us around that is the - well, two key issues. One is the extent to which the system is responsible. In other words, whether they can, hopefully in consultation with the parents, extending to a whole range of other people, but whether appropriate arrangements are made within the system or whether you're talking about within the school, and then if it's within the school, it then becomes a matter of the funding mechanisms within the system and whether or not the school actually gets extra money. If the school has to cope, then really the school is in no different situation to your small, independent school.

MRS OWENS: Yes.

MR MARTIN: It can be placed under huge hardship, and that, of course, affects others standards in the school and the general service of the school.

MRS OWENS: And also it would also be then quite variable across the board.

MR MARTIN: Yes.

MRS OWENS: It would be different for big schools than they are for smaller schools.

MR MARTIN: Our major criticism of the standards is that it doesn't sufficiently clarify the responsibility between system and the school and the teacher.

MRS OWENS: With the independent schools, I mean, if there has to be some adjustment, then there's potential for the schools, albeit reluctantly, to increase fees. Now, with government schools, you don't have that option, so what it really means is it's going to reflect on the educational facilities for all the other - for everybody, that's right.

MR MARTIN: And that is an issue, I mean, that goes not just to costs but to other issues as well, the effect on all the students.

MRS OWENS: I was just going to ask Catherine if - you've been sitting there quietly, and you're the federal women's officer. Have there been particular issues that you've been concerned about in the context of this area?

MS DAVIS: Not in a general - not in a specific sense, no. I mean, I'm quite new to the role, but I'm happy to be supporting Roy's comments today. Certainly there's always issues as a women's officer representing the women teachers at school. There is a high proportion of the teachers that are dealing with students with disabilities that are more often to be women who, you know, are basically taking on carer roles and things like that. So that's where my interest in the area does lie in one sense, but in a general sense, as Roy said, it's one of the highest concerns that teachers do raise, and the point of the frustration that comes about from teachers absolutely wanting to make sure that the best outcomes for the students are ensured, that they can't always deliver because of their own training or because of the opportunities and resources that are in the schools, that frustration becomes quite apparent in these cases and it's a high level of, yes, dissatisfaction that the system - as Roy is trying to delineate the difference between the schools and the system, that that's the system's failure to be able to ensure that both the students and teachers are getting the best out of the resources that they do have or don't have.

MRS OWENS: I think we've covered all our issues that we wanted to talk to you about. We've talked about the funding and we've talked about unjustifiable hardship, standards - - -

MS McKENZIE: Are there other matters you wanted to raise with us?

MR MARTIN: I would just simply like to reiterate the fact that at the chalkface, this is manifesting itself in stress for people, for teachers, for students with disabilities, students not with disabilities, and for parents, and our position all along has been to try to get to a situation where we can get the best for everybody concerned without confrontation and aggression, which unfortunately does occur around some of these issues. That way you've got processes which are consultative and open rather than confrontational. Occasionally, and I'm not going to generalise, but certainly occasionally there are advocates for disabilities who believe, and it may be in some cases through particular experiences, but believe that they have got to be confrontational in their approach in order to achieve anything. I think it's regrettable if they feel that, and that what we've all got to do is to find a way through these issues that doesn't leave particular people with the huge stress of becoming test cases in court or in HREOC and all of these kind of things, and we've got to find sensible processes that take account of all of the different considerations in a very complex issues. That would be my major please in terms of where we go.

MRS OWENS: There was just one other area that's covered in the act, and that's the area of harassment.

MR MARTIN: Yes.

MRS OWENS: The act as it's written at the moment prohibits harassment of people with disabilities by staff but not by the other students, but the school can be held indirectly responsible for that sort of harassment, and I suppose you'd say that that's another stress factor on the staff. Do you think there's a way through that particular issue?

MR MARTIN: Well, I mean, I would argue that one of the best features, apart from benefits to the student themselves, but students with disabilities in classrooms can be an educative experience for everybody, and part of that educative experience unfortunately is learning to understand other people and their particular situation, and so in one sense it's part of the normal learning process. Now, it's unfortunate that sometimes in the learning process, people get hurt.

MRS OWENS: It's an extreme - - -

MR MARTIN: When I was teaching, I can remember an incident where it became a break activity to dunk someone with a hearing aid in the toilet. I mean, that is not condoned and teachers have to deal with it and do deal with it, and they deal with other instances of bullying in a whole range of circumstances, but without in any way suggesting you welcome the incident, it's part of growing up and of learning to deal with things, and in some ways you're better off dealing with it as part of the educative process than having to be isolated and deal with it in society at a later date and so on, and I would hope, and I do believe, that in most cases where there are students with disabilities in classrooms, all of the students benefit and are better people for having the experience of those people. I think - I guess that would be my answer there.

MRS OWENS: That's a really interesting perspective on that. Good, thank you. Are there any other issues that you think that we should look at that we haven't covered with you? I mean, there are other issues that we have read in your submission, so we haven't gone through everything you've raised in your submission, but is there anything else that you think we should be highlighting?

MR MARTIN: I think we've covered most things in between this and the submission, and we've put most of what we would like to say there.

MRS OWENS: Okay. Well, thank you both very much. That concludes today's scheduled proceedings, but I'm wondering if there's anybody who would like to come forward today. Yes? Would you like to come forward? We'll just stop for a minute.

MS DON: My name is Elizabeth Ann Don, I'm appearing as an individual and I'll make statements about the DDA and conditions pre-DDA growing out of my experience.

MRS OWENS: Thank you.

MS DON: I'll start off with a philosophy - a statement of medicine first. I believe eventually medicine will boil down to what will cross a tissue, under what circumstances and when, both in causation and cure. The second statement is if a society or societies demand a standard of living so that trauma, eugenic effects and illness result from this standard then that society must bear the cost of this structural, institutionalised violence. Those affected must be given a fair go so that attending to daily living is not exhausted, there is equity of access to those activities, ways of being social interaction and human dignity that to many another is an expected given, not a grudging gift, to the defined unproductive.

The Reverend Dr Brian Howe was the person who constructed the Disability Discrimination Act and his training was both as a Christian minister and as a sociologist. So the concept of institutionalised structural violence is a sociological concept. It can be seen theoretically to include the violence perpetrated by standards where a standard that is good for one thing does harm to another. I have a couple of examples which I will go to in my written submission but first I'd like to say it includes the changing of the familiar (indistinct) landmarks, such as our old banks, our old post offices, and if you're in your 60s, 70s, 80s and you're not dementing yet but this was your familiar path, if these are all changed to a bland, new type of design and your footpaths have changed and your trees have changed and your street signs have changed, you may become disorientated much sooner and not be able to look after yourself and attend to daily living.

I've nursed dementing people and their memories go back 40 years and they remember what was there 40 years ago, not what's there now. So this modern change, the pace of modern change is limiting to the elderly and limiting to their equity of access in our society. Structural institutionalised violence may arise from extended ideation of misunderstood tenets of belief, as in religion and biology. In some applications historically we have seen cruelties imposed by social Darwinism, eugenics, fear and wilful ignorance. These have arisen and been discussed in our national papers with the International Genetic Conference in the last week or so.

Now, I'm four feet 10, I'm legally one of the little people. I suffer left temporal lobe epilepsy. I've post-traumatic stress syndrome, I've got half my hearing and I'm losing my sight. All those conditions, except for post-traumatic stress syndrome, have been mooted as, "You should have been aborted," and I want to go on record to say that there is in Australia in genetic counselling and there in the community a thread of believing in eugenics, and I find it repulsive and I find it hurtful. So I'll move on to my own story. My father was killed in World War Two just after I was born. My maternal grandmother who'd married a bloke from the Barossa Valley, a German fellow, raised me whilst running a cafe single-handed in North Queensland. My mother went off nursing.

When I was five I was run over by the school bus. The driver had recently had eye surgery. He was unaware he'd knocked me down and run me over. His sole passenger and other witness were given paid holidays to leave town whilst the inquiry was on. There was no compensation. I had a fractured pelvis, head injuries, massive internal injuries. I have been left with left temporal lobe epilepsy and deafness which was not diagnosed till adulthood yet perceived as truculence in childhood and punished, both physically and in other ways. The trauma has left me with post-traumatic stress syndrome. I have an unandrogynised skeletal structure from massive kidney damage and I had to swim a mile a day from the time I was six to get my muscular structure back to be able to walk.

I had music, speech and drama training through AMEB so that my face-to-face presentation is acceptable. But when I grew up there was no special rehab, no physiotherapy, no oral training, no speech therapy - none of that existed. I went to a state school until I was 12 and then I went to a Church of England boarding school and there was no quarter given whatsoever, okay. As an epileptic you have massive internal fears that just flood you so that when you're harassed I now look on it as conditioning and I must pretend to the other I do not have this fear but I can be intimidated.

Despite this, I trained as a nurse at the Alfred Hospital. I married and I had three children by Caesarean section. I nursed my dementing mother-in-law until she died. My husband was in the army on call and then he was a federal policeman on call. When I nursed, raising my family, I was on call seven days a week, 365 days a year for 10 years till I took long service leave. My IQ has been measured above 30 and my memory is in the top 2 and a half per cent of the population. I am currently completing a masters in psychoanalytical studies. I've completed my analysis. I cannot hold a driver's licence. I've been denied desk research positions in an epilepsy organisation because I cannot produce a driver's licence. There were no driving duties. This has gone on and on and on, "You must have a driver's licence."

MRS OWENS: Why?

MS DON: It's used as a security check to see if you're an adrenalin freak, if you have a bad driving record, you don't pay your fines. It's used as a character check.

MRS OWENS: There's a lot of characters driving around that drive really badly.

MS DON: They're nutters - excuse me, they're nutters. Anyway, I now hold a passport to access most ordinary things in life in my own country, including getting a rubbish bin back from the Fitzroy Council when mine was stolen.

MRS OWENS: You have to produce your passport?

MS DON: I had to produce a passport because it goes like this: the bin was stolen; the whole city collection had been privatised, therefore the collector bore the cost. I had to make a statutory declaration that it had been stolen. I went down to the police station and a nice young policewoman said, "You must produce a picture ID." Wrong, you do not have to produce a picture ID. Although I was on the local police safety committee she wouldn't call in an officer I knew and he knew me, she made me go home and get a passport. I'd only had it two days. While I was home I rang up the minister for the environment's office and I rang up the federal parliamentary secretary for immigration and explained I was being made to use this external international document to get a rubbish bin back. I went back to the police station and got my stat dec signed and said nothing and the rubbish bin was at my front door the next day.

In my last position nursing - the institution has now been shut down and decommissioned, it was a church institution, it was an old age home, it was a specially commissioned dementia unit - I blew a whistle on elderly people being locked in rooms without community orders; over-medicated; tied in bed all night without toileting and tied up with pantihose in a chair in the dining room with lights on all night. Now, I'd been nursing at this place for about eight or nine years, then a wing was redeveloped by an architect and a whole lot of new staff came in. The new staff were a group untrained - that was to cut wages - and then the others weren't general nursing staff, they were from intellectual disability and mental health. The whole culture changed overnight.

What was supposed to be an experimental, drug-free unit, the first in the world and the first in Australia, rapidly became an over-drugged unit. I devoted one day a week voluntary to field research. It was the first field research in the world looking at the behaviour and the effect of families on people with dementia - one group at home not institutionalised, and a group who were institutionalised. This research found it made no difference at all to those with dementia, where they were, but it made a hell of a difference to the families, and I won't go into the tragedy of those families. It's shocking.

Anyway, I was trying to finish my postgrad degree in psychology and I left my husband. I took three months' long service leave and the two years of leave that were owed to me. When I returned I found that the patients were tied up, some patients were stripped of their pyjamas. There would be an extra drawsheet put over the bottom sheet and a rubber mat, another drawsheet put over and a rubber sheet and the bedclothes pulled up and they would be in an operating gown. They would be tied in at 11.30 at night and these things would be removed at 5.30 in the morning and they wouldn't be attended to all night and the staff would sleep.

This change in culture came while I was away on leave. The boss was away on a Churchill fellowship. They knew I was going to blow a whistle, I was going to blow it to the boss when she came back. I did and she didn't believe. But in that two and a half months before she returned I was harassed through my hearing. A staff member would go out of the room, mutter something and come back and scream at me, "I gave you a direct order, why didn't you obey?" In my union that's instant dismissal. The other thing, I would be put between the bed and the wall - it was a policy of normalisation, so people brought in their own beds from home. Well, re-making a bed, the bed would be slammed into my knees. I'm getting two new steel knees within the next three months. I've suffered intense pain. At the same time they would flick the sheets with raised diamond rings, and I've got scars all over my corneas and I've got dry eye syndrome.

I took sick leave, what I had left, and I went to the union and the union said, "Right, we'll fight this case. You're to go on stress leave." After 18 months of harassment, being sent to psychiatrists and a few other things - one of the really beaut ones was the experience of having my back x-rays done and the doctor naming the bones in my spine that were normal, leaving out all the ones that weren't, and saying the x-rays were normal. The x-rays were a beautiful picture, of course they were normal. It was my spine that was in a mess. That was the sort of thing that was done in the WorkCover system.

There is a High Court decision saying that a medico-legal assessment given by any medical practitioner should be able to be taken to another practitioner and without any addition to that medico-legal assessment or any detraction, must be able to treat that person for the differing things. That's a High Court decision. There were so many bad medical reports in Victoria that the health commissioner was flooded with complaints and the health commissioner can no longer accept complaints about inefficient or wrong medico-legal assessments. So there's a whole section of the community out there that is not protected, who may be injured at work and also I understand if you reach 65 you're no longer covered by WorkCover. I feel very strongly about this.

Anyway, I endorse the recommendation of the Guardianship Board that criminal sanctions should be applied to those who harass a person through their disability so as to cause injury or loss. I also endorse the High Court decision which I believe has been rescinded in the WorkCover areas that any medico-legal assessment by a medical practitioner should be able to be taken to another practitioner and without any addition or detraction that report be able to competently treat the injured person's condition.

Under the institutionalised violence, I also sat on the Yarra City Council disability reference committee. There is in the disability world a hierarchy of aristocracy with those in wheelchairs at the top, then come the blind, then come the deaf, then come those with mental health problems and at the very bottom are those with neurological disorders. Within those splits there is also a gender hierarchy and there is also an ethnicity hierarchy as well. It's very interesting for me to go to a migrants conference to find that I'm on the side talking to women and we have so many things in common that we are trying to get put on the agenda it's not funny. I've lost track of my thoughts.

MRS OWENS: You were talking about the hierarchy.

MS DON: Yes, the hierarchy. So I've also sat on a national hook-up and found that people have said, "We don't want deaf people at the table because they look stupid and they bring the rest of us down." This is at conference tables at Canberra and this was when I was on a peak body. I don't know what we can do. There is within the City of Yarra anyway some wheelchair-users who belong to another committee in another organisation, came along and said, "We want the footpaths - so that we can use them." The footpaths are disgusting but the federal building standard, disability standard, says that any lateral surface that meets there must be no more than three millimetres difference.

Now, three millimetres difference, I believe, was meant to apply internally in certain situations. To apply it to a road in a footpath is stupid, it's stupidity. Anyway, that was used to break heritage law - the DDA overriding heritage - so that all historic bluestones in Carlton, Fitzroy, Collingwood, Richmond - City of Yarra - be ripped up and everything sealed with concrete. The engineers want it all sealed with concrete. The City of Yarra rests on clay. Now, we're at the end of a five-year drought and maybe another year of drought. Clay shrinks in drought. When clay shrinks, buildings crack. You cannot insure for a cracked building and as the council would be complying with a statutory demand, the building code under the DDA, they cannot be taken to court and sued.

I do not have the money to fix my house up if it cracks if everything is put under cement. The laneway behind me has been cemented over and the guttering in front of the house has been cemented over and that house has cracked. So this, I believe, comes under the heading of Institutionalised Structural Violence. Some members in wheelchairs of this committee - we've met with residents in the street several times, big free-for alls. Some residents believe bluestones are dirty and accumulate rubbish and they came to an accommodation whereby, okay, we'd use cobbles that look like bluestones. They could be laid with an even surface and where there was a dip in the footpath across a carriageway, we could tarmac that in to make it even so that the wheelchair wouldn't tip.

I believe that in asking for standards we have what we call in psychology "an operational definition". Does this work so that it does no harm? But if we start going down into this minuscule measurement, such as three millimetres difference between two lateral surface, it's going to be a lawyer's picnic, it really is. So that's all I've got - apart my partner who has got a defibrillator, and that's very complicated electro-physiology, and I need to refer to research and a few other things, but what happened there she was nearly killed through a cardiac surgeon's incompetence. I had to call an inquiry. The infrastructure - the ambulances have to take you to the nearest hospital. The nearest hospital may not be your treating base, it may be the base for a different manufacturer. They do not have a cardiac reader. The cardiac surgeon will refuse to contact your training hospital, and when I blew the whistle and there was an inquiry they found this had happened many times and patients had died.

If your defibrillator went off in the country and you were brought in by helicopter, you went to your right treating base. I believe that Mr Packer does not now have an internal defibrillator, he has an external defibrillator and a nurse on duty beside him 24 hours a day. Thank you.

MRS OWENS: Thank you very much. That concludes today's proceedings and I'd like to thank you very much for that.

MS DON: Thank you.

MRS OWENS: Is there anybody else that wants to appear today? No. There's other opportunities. We will be resuming tomorrow morning at 9 am.

AT 5.25 PM THE INQUIRY WAS ADJOURNED UNTIL
THURSDAY, 24 JULY 2003

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