



**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 SYDNEY ON FRIDAY, 18 JULY 2003, AT 9.14 AM**

**Continued from 17/7/03**

**MRS OWENS:** Good morning, and welcome to the public hearing for the Productivity Commission inquiry into the Disability Discrimination Act 1992, which we will refer to as the DDA. My name is Helen Owens and I am the presiding commissioner on this inquiry. My associate commissioner is Cate McKenzie. The hearing will have breaks - morning tea, lunch and afternoon tea - and we will 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 impact of the DDA on people with disabilities and on the community as a whole. Among other things the commission is required to assess the costs and benefits of the DDA and its effectiveness in achieving its objectives.

We have already talked informally to a wide range of organisations and individuals and the purpose of this hearing is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. We have been holding hearings in Sydney this week and we'll be holding hearings in Melbourne next week. We have already held hearings in the remaining capital cities. We will then prepare a draft report for public comment, which we will release in October this year and there will be another round of hearings after interested parties have had time to look at the draft report.

We like to conduct these hearings in a reasonably informal manner, but I remind participants that a full transcript is being taken. For this reason and to assist people using the hearing loop, comments from the floor cannot be taken because they won't be heard by the microphones. If anyone in the audience does want to speak I allow time at the end of the proceedings today to do so. Participants are not required to take an oath, but are required under the Productivity Commission Act to be truthful in their remarks.

Participants are welcome to comment on the issues raised in other submissions. The transcript will be available on the commission's web site in Word format following the hearings. I now invite our first participant this morning, the Australian Chemical Trauma Alliance Inc, and that is Ann Want from that organisation. Ann, could you just repeat your name and your position with the Alliance for the transcript?

**MS WANT:** My name is Ann Want and I'm national coordinator of the Australian Chemical Trauma Alliance and I am appearing here, but in the capacity as an individual and representing the Alliance.

**MRS OWENS:** Ann, thank you, and thank you for the very detailed submission

and we've now got a submission with a number of appendices attached, which I have worked my way through, so thank you for that. I understand, Ann, that you just want to add some further comments to that submission?

**MS WANT:** Just a few further comments. Basically, as I hope can be seen by the submission, multiple chemical sensitivity is definitely an unmet need in our society today. Many people are suffering. I have given documentation of the researches, the percentage of society suffering from it, to varying degrees. It can be dealt with in many cases through - like at present how people, sufferers of MCS, have no access to hospitals, education, public places, et cetera, due to their sensitivities, and in many cases they can be accommodated. Quite basically they're prisoners of the attitude of people around them.

Basically the quality of life of people with MCS is completely dependent upon the attitudes of everyone around them. There is a complete lack of political will to aid chemical sufferers; chemical injury people have been requesting a lot of things over the years, mainly knowledge of what is being sprayed around them and the chemicals that are involved in products, et cetera. A couple of examples of this lack of political will: we've presently been involved over the years through a couple of organisations with what is now called the National Pollutant Inventory, which is to measure the pollutants in our environment, the knowledge of which will help a lot of MCS sufferers - just to know what they are being exposed to in their environment.

Presently Australia's NPI requires the reporting of only 90 pollutants compared to the US's in excess of 600. This is extremely disturbing in the light of reports, especially from the World Health Organisation: their reports Children Health And The Environment: a Review of Evidence, and another report Polluting our Future, that links chemical pollutants and environmental pollutants to child development and their learnings. I have got copies of the reports here.

**MRS OWENS:** Yes.

**MS WANT:** That type of knowledge, as we've found with our children with MCS, is extremely important, so on an international basis we've got this work occurring, but our Australian government chooses to ignore it. An example of that has been our two regulatory authorities we have got at the moment - the national registration authority that is now the Agricultural and Veterinary - whatever. I've forgotten the new name - which look into agricultural and veterinary chemicals, and NICNAS which looks into the industrial chemicals.

We've got chlorpyrifos that our organisations have been fighting for a long time. Chlorpyrifos has been withdrawn for anywhere - basically anywhere that chlorpyrifos comes into - where children come into exposure for chlorpyrifos - it's

spraying around the homes; it's spraying on the - use on the food chain, et cetera, et cetera - as being banned and withdrawn from use in the US, based on the effect it is having on the child. Our Australian authorities are still ignoring all of that international research and will not - well, we've insisted - called for reviews, et cetera, and they're not looking into it. Sorry. They're ignoring the research that is out there. We found the same with another chemical 2-butyoxyethanol that we have also been involved with. It's used commonly in industry. I've been involved with it since 1992, when I first found it being used in the schools.

**MS McKENZIE:** As a cleaning - - -

**MS WANT:** It's a cleaning product. It's used in paints. It's also used in a lot of medication; in rubbing agents, to make it move through the skin. It's being banned overseas - in Europe, in France - and we got as far as a WorkCover inquiry into it.

**MS McKENZIE:** In New South Wales?

**MS WANT:** In New South Wales a couple of years ago and basically all they did was look at research - did a literature search on the research that was available, but chose what research they listened to, and ignored the human health data that was being developed. I am making comment of this because it just highlights the lack of political will by our regulatory authorities to control chemicals that eventually people with chemical sensitivities are being exposed to. If chemicals were controlled a bit better in Australia in a lot of cases their lives would be made a lot better. There just seems to be not only complete lack of political will of our authorities to acknowledge the problem - and I have touched on that through my submission - but also a complete lack of political will to address the chemicals through the regulatory system which exists in Australia today.

Another thing we are finding, too, with chemically-sensitive people is the ineffectiveness of the Disability Discrimination Act, as such. To put it in a nutshell, what we feel is that it's aimed at businesses. It's not aimed at the end user, the person. With it people are forced - especially with chemical sensitivities - to throw themselves at the legal system, which is open to interpretation. Justice does not seem to be done through our legal system, as such.

**MRS OWENS:** Is this because there is an imbalance between the resources that those individuals may have and the resources that the companies can throw at the issue?

**MS WANT:** Yes. People with MCS generally do not have the money to pursue legal action. They don't have the health in order to be able to withstand the protracted hearings. Recently, 2000, there was one of the few successful cases, but it

took that couple 12 years from beginning to end of just staying in there, staying within the system, to obtain that success.

**MS McKENZIE:** That case was where?

**MRS OWENS:** Was that with the Anti-Discrimination Board in New South Wales?

**MS WANT:** No. It was just a legal - - -

**MS McKENZIE:** There was a court case?

**MS WANT:** A court case. I've got a transcript here if you would like a copy of it.

**MRS OWENS:** Is there also an issue with people using the DDA that if they did have to go through conciliation that they may have trouble actually physically being, say, in the city or in a room with other people? Those sorts of issues arise?

**MS WANT:** Yes. Access to public places. Not many people would be able to come to the city and sit in a room as I am able to, due to their sensitivities - access that way, et cetera.

**MS McKENZIE:** That makes it particularly difficult for children with this condition in education, because of course, traditionally, education happens in classrooms.

**MS WANT:** It does. Children with multiple chemical sensitivities are very much at the moment at the will of the people around them and the ability of their parents to fight for them. There are some attempts to integrate these children but - - -

**MRS OWENS:** In what way? Explain what sorts of attempts are done. Maybe you could tell us a little bit about what attempts were made for your own two sons.

**MS McKENZIE:** For your kids, yes.

**MS WANT:** With my children - to integrate them into the primary school; number 1, they went to a small five-teacher school in the country. I had to go in and eliminate all toxic cleaning products and reintroduce safer ones - less toxic ones - which they did do. Teachers did not wear perfumes in the school. No pesticides were used. We found other, more natural ways of dealing with any outbreaks that did occur, and the council and the electricity people did not spray within a kilometre of the school in school time, and if they did need to spray they did it at the beginning of holidays.

What is occurring with children today is generally the schools that do accommodate them take those facets into consideration, as well as refraining, if they do need to spray, at the beginning of school holidays, et cetera, and any maintenance work through the school holidays. Unfortunately some children, after painting, can't go back into the classroom situation, et cetera.

But there is no directive from the department as to the integration of these children. It's up to the ability and the personality of the parents to fight, and it's an everyday fight to keep their children in the system, because people forget, people don't understand the impact it could have on the individual child.

**MS McKENZIE:** Do you think it's partly because the Department of Education is not treating this as they do other disabilities or is it because they're not willing to undertake - - -

**MS WANT:** They don't know how to handle it.

**MRS OWENS:** Or don't understand?

**MS WANT:** Quite frankly, they don't know how to handle it. A few ideas have been thrown around over the years as to whether they build an environmentally friendly school in each area or integrate the children into the school generally. They know that by integrating the children into the school generally it will cost a bit of money, but all children in the school will be protected from chemical exposures, but you've got the political forces that come to be from the chemical industry, et cetera, that then impact on that type of decision.

Within the Education Department again I've worked intensely with it for over 10 years in different avenues, and although I'm finding ministers that are sympathetic to the cause, individuals in the department sympathetic to the cause, they will not put anything formally down in writing as policy. For instance, when the inquiry into chemicals in schools was formed - when that committee was formed in 1995, after the toxic playground conference, the Education Department was inundated with pressure from the chemical industry to be involved and to steer it, and basically they've got outside pressures other than the politics of it. Again, as I said, we've had a lot of support from people like John Watkins, John Aquilina, over the years but - - -

**MS McKENZIE:** Who are those people?

**MS WANT:** Sorry. They were the ministers for education, sort of on a one-to-one basis. John Watkins actually launched a book that would go a long way in protecting our children, which is Integrated Pest Management in Schools, but we're still not

seeing anything from the department, in general, from the bureaucracy as such.

**MRS OWENS:** So you're relying on really grassroots support from the individual schools and individual teachers.

**MS WANT:** Yes.

**MRS OWENS:** And you were fortunate enough to have a reasonably positive response to your concerns, but it may not be necessarily the case in some of the other schools.

**MS WANT:** That's right. You know, like, we had to unfortunately threaten with - you know, we pointed out that they were assaulting our children by using these products. It wasn't an easy road.

**MS McKENZIE:** Did you use the Disability Discrimination Act as a threat?

**MS WANT:** As a threat, yes, but - - -

**MRS OWENS:** Do you think that helped? I mean, it's probably a combination of circumstances that swung it around, but do you think it was part of the pressure?

**MS WANT:** It helped. When we accused them of assaulting our children, and that we would take action against them if this assault continued, there was a - it sort of added to a whole range of things. In a lot of cases too - like at one stage, one incident, my child was exposed to a whiteboard marker deliberately to see how he reacted, because, you know - - -

**MRS OWENS:** Was this by a teacher or by another child?

**MS WANT:** By a teacher. I was called up to the school. Andrew was curled up in the foetal position, his pupils were dilating, he was whimpering like an animal and the teacher was standing there with goose bumps all over her. They deliberately exposed him to see what it would do to him. In a lot of cases from then on it was, "Yes, Ann, no, Ann, three bags full, Ann. We will change it."

**MS McKENZIE:** But, see, that really shows a complete lack of understanding, doesn't it?

**MS WANT:** Pardon?

**MS McKENZIE:** It shows a complete lack of understanding of - - -

**MS WANT:** Well, this is what is happening. We've got incidents of kids that have had to be removed from school, because children have not understood their disability and they have come up and just emptied deodorant cans all over them, perfume - sprayed cans of perfume all over them, completely destroying their - well, further sensitising them to the degree where it made the difference between them being able to go to school and not. A lot of our children are involved with distance education, because they just can't go to school. The attitude of children around them is very much - we sent our children to a Christian community school, because we felt there might have been a better chance of them - with the attitude of children around them compared to a state school - and we have found that quite successful, et cetera.

**MS McKENZIE:** But whether or not the school makes accommodations for these children is very much on an ad hoc basis school by school.

**MS WANT:** It is an ad hoc basis, yes, and there is nothing coming from the department, but that's everywhere. We're finding it in hospitals, as a result of the work that we've been doing, in protocol. There are some hospitals that will attempt to accommodate these people, other hospitals that won't. There is nothing coming from the top to police it as such.

**MRS OWENS:** So you've also gone to - I don't know what the department is called in New South Wales. Is it Department of Health or Department of Human Services?

**MS WANT:** We have been trying to work through the Department of Health in every state for many years. That was highlighted in New South Wales with the case of the member of parliament, Alan Corbett, whose wife has MCS, and he naturally fought for hospital accommodation for her. That documentation is right through the Hansard.

**MS McKENZIE:** Many of the submissions say that often people with disabilities receive better treatment where someone has a personal involvement through their family or their children.

**MS WANT:** Yes.

**MRS OWENS:** What would hospital accommodation involve? Would it involve having special areas? I mean, apart from the cleaning products and so on - - -

**MS WANT:** Yes, a special area. It would involve an environmental unit. A lot of hospitals in Canada are now setting them up. Getting back to the accommodation in schools in Canada, they are developing an environmental unit in every school where children with this problem are in all the time or come to for refuge. With hospitals, it will require a unit to be set up with purified air going in, knowledge of the

individual's food sensitivities, the cleaning products, no wearing of perfumes around, laundering of their bed linen, et cetera, in less toxic materials - - -

**MRS OWENS:** There are things like bandaids - you know, the sorts of material they put on people's skin. You talked about lotions before, but there is also - some people I think have reactions to some of those other strips and so on.

**MS WANT:** Yes, to bandaids.

**MRS OWENS:** So to have other sorts of materials available.

**MS WANT:** Yes. A lot of people - they would need more in - porcelain-type masks instead of the plastic rubber-type masks.

**MRS OWENS:** Is there a problem with restricting the use of cleaning products in terms of other patients, because we've got to think about all patients and they need to clean and sterilise areas in hospitals - - -

**MS WANT:** Yes, there is.

**MRS OWENS:** Otherwise you're risking staph infections, for example.

**MS WANT:** Yes, that's a problem that we're looking into. You've got steam cleaning. You know, is that a possibility? The thing is, it needs to be looked into. It needs to be explored and we're not even getting to base 1 to have it looked into, to have it explored. When I was working through the schools the Tempo Cleaning Service up on the north coast have trained four cleaners in steam cleaning to put into schools with children with MCS, and they say that their steam cleaning will do everything including toilets, et cetera, in a school situation. So the avenues are there. They just need to be investigated.

**MRS OWENS:** What is happening in Canada? In Canada, with hospitals, they are making inroads.

**MS WANT:** They are starting.

**MS McKENZIE:** They have made accommodation in hospitals.

**MS WANT:** Yes.

**MS McKENZIE:** Do you know what kind?

**MRS OWENS:** You've got some details there?

**MS WANT:** I've got some documentation here. If you would like, I'll photocopy it.

**MRS OWENS:** So you could table some of those documents, could you?

**MS WANT:** Yes, they are readily available on the Web. I can give you the web sites to each one.

**MRS OWENS:** We're interested in issues like reasonable accommodation. There is the issue of costs of reasonable accommodation. I mean, our key concern, of course, is the operation of the act and how that is applied, but these areas - we're interested in why people don't come forward with complaints, or whether there should be more systemic inquiry into some of these issues.

**MS WANT:** I feel with multiple chemical sensitivities a more systemic inquiry is necessary, because the intimidation that goes on is just incredible. As I mentioned in my submission, just with children with multiple chemical sensitivities the way the medical profession deals with it, they don't know the answer to it. They either don't know, or they don't want to know. They don't want to treat it, or they can't treat it, I don't know, so they turn on the parents, intimidate the mother, accuse her of Munchausen by proxy. I've got many cases at the moment of parents complaining of that type of treatment.

**MRS OWENS:** Does this come back to the training of the medical profession?

**MS WANT:** It comes back to the egos of the individual. You know, that type of intimidation runs to the roots, psychologically, of a lot of women. A lot just sort of retreat into themselves. The tragedy there is that a lot of the children do not receive the medical care that they need, because in a lot of cases, as happened with us, there was no way I was going to go back to that hospital, no way was I going to face those people again, and we were just lucky enough to have a very supportive paediatrician.

**MS McKENZIE:** Who was understanding.

**MS WANT:** He was understanding, yes.

**MRS OWENS:** Do you think this is just a lack of understanding, or is it more than that? It is indirect discrimination against people, or children, with multiple chemical sensitivities?

**MS WANT:** I think it's a direct discrimination. At the moment if you mention chemical injury in this society, if you mention that chemicals are causing you problems, with the hierarchy there just seems to be an hysteria that is set up, "Oh, it's

psychosomatic." They blame it back on the individual, back on the parent. "Chemicals aren't causing problems because they're so widely used." I think I mentioned in my submission that they have become such an integral part of our society - you know, what I have never ever understood with them is that when you start looking into the research data with these chemicals, they show the central nervous system disruption it causes, they show the cancer it causes, but you dare present to a medical profession or any of our authorities with these problems and they don't want to know about it; they can't handle it. They don't want to handle it and you're intimidated; you're not - et cetera.

**MRS OWENS:** You mentioned in your submission that - I think it was Germany have included MCS in ICD10.

**MS WANT:** Classification, yes.

**MRS OWENS:** Classification. I don't know what's happened in Australia. Are we still with ICD9 or have we gone to ICD10?

**MS WANT:** We're with ICD9. We're going to ICD10 and we have submissions in four MCS to be included in ICD10. I haven't heard as yet - I think July-August - it was around about now that they would be coming down with their recommendations. Many submissions went in both from individuals and sympathetic individuals within the medical profession for it to be included, but we haven't heard as yet.

**MRS OWENS:** So the submissions go where? Do they go to the Department of Health and Ageing, or is it - - -

**MS WANT:** Department of Health, I think. Somebody at the Sydney University was the person who all the submissions went to. I've got their details at home if you want that.

**MRS OWENS:** I'd be interested to see what the outcome of that process is, if it's due any moment. It might be quite timely for us just to see it and it would be interesting to see whether the arguments are accepted and, if not, why not.

**MS WANT:** Yes. The precedent has been set overseas, why not here?

**MRS OWENS:** I think once you've got that in a recognised classification, then other things possibly can follow from that because once it's in there they would measure it. The ABS would be measuring it, so would the Australian Institute of Health and Welfare, because it becomes part of the measurement system. Then you can start to pin this down and that leads to greater recognition. So then you've got more clout when you go back to the regulators. It's not the sole answer, but I think it

would actually help a lot.

**MS WANT:** Yes, this is what we feel; once we have recognition and this is one thing that we've been trying to fight for: recognition through the Health Department. I've got the examples of some of the lobby letters that we've been sending in to the Health Department over the years for recognition of this because, as you said, once recognition is gained it will be easier to access education and housing, and rights of individuals with MCS will be more recognised.

For instance, it's happening in areas overseas. I think in my submission I included places in the US where public places are now perfume-free zones, schools are perfume-free zones, et cetera.

**MS McKENZIE:** But not in all places in the US?

**MS WANT:** No, in individual cities and individual areas. As I said, it's also ad hoc there, but it's coming. You know, it's possible. It's not as if it's not impossible.

**MS McKENZIE:** There are real difficulties as far as discrimination is concerned because whether or not your disease happens to be included in an international classification is, in a way, relevant to whether or not you can be discriminated against. If you are treated in a particular way by an employer or an educator or whatever, because of some group of symptoms, whether or not they think you are lying about them or have made them up, the effect on you is still the same.

**MS WANT:** Yes.

**MRS OWENS:** I think at least recognition gets you to the first step. While it's not recognised - you can never account for ignorance and lack of understanding.

**MS WANT:** At the moment we haven't even been able to get on to first base with it.

**MRS OWENS:** You have, in one sense, because you do have that letter from Elizabeth Hastings, and you've also got the frequently asked questions that acknowledge that it's part of the definition of disability under the DDA, so you've got to first base there, but it's a matter of getting that message out into the community more broadly and every little bit helps, but as Cate says, it doesn't necessarily change behaviour in some quarters, but it's moving in that direction.

**MS McKENZIE:** There are some other troubles there. The frequently asked questions are not a court case. They're not a definitive interpretation of the act. What they do at least indicate is that the commission - as long as it obeys its own

answers to its own frequently asked questions - won't decline the complaint if a complaint is made. But that doesn't actually tell you what a court might think at the end of the day.

**MS WANT:** Yes. One thing that really highlighted it, I think, is when I went to the Human Rights and Equal Opportunity Commission over my children, they wouldn't put anything in writing to me, but the comment when I rang them - after protracted correspondence I went and presented my case to Chris Sidoti at one time, who was very sympathetic but, you know, what can they do? But the comment that rang in my ears and still does was that I was told that they couldn't help us because they were a government-funded institution and they couldn't go against government policy and that no law had been infringed at that time.

At the time my child's health was going down quite rapidly due to a neighbour spraying on his property, who was aware of my child's situation. You know, we just couldn't get help anywhere. We ended up settling that issue in the long run, but it took two years.

**MS McKENZIE:** Was that settled through the commission?

**MS WANT:** No.

**MS McKENZIE:** Or just through private discussion?

**MS WANT:** Through private discussion, et cetera. We ended up having a lot of people working - to come through different departments to come to some sort of settlement there, but we succeeded anyway, but that was the attitude of the Human Rights at that time, and many submissions have gone into the Human Rights and International Human Rights, but where do you go?

**MRS OWENS:** I think we've just about covered all our issues that we wanted to cover with you. Are there any other issues you wanted to cover with us?

**MS WANT:** No, basically, again, as I said, there is a lack of political will to address the problems because of the chemical issue and education about chemicals and what they do not only to the environment but to human health has got a flow-on to anybody with MCS and it will prevent a lot of MCS from developing but there's just complete lack of political will at the moment for that to occur and again - and education programs. The support groups - at the moment there's quite a few. There's one running out of Perth, one out of Queensland, New South Wales and Victoria. They are all run by volunteers using their own time, membership money which barely covers postage and newsletters, et cetera. The organisations need funding in order to be able to travel to forums instead of the cost of everything being borne by

the individual to present cases and education funding. They are all necessary.

**MRS OWENS:** Thank you very much for that.

**MS McKENZIE:** A very helpful submission.

**MS WANT:** Thank you for the time.

**MRS OWENS:** As I said to you before we started, we're getting a very consistent picture about this issue from a number of people as we've been doing our hearings, so thank you very much for coming.

**MS WANT:** Thank you.

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

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**MRS OWENS:** We will now resume. The next participant this morning is Dr Jack Frisch. Welcome to our hearings. I'll ask you just to repeat your name and the capacity in which you're appearing, for the transcript.

**DR FRISCH:** My name is Jack Frisch. I'm a lecturer in economics at the University of New South Wales and I'm interested in particular in writing a book on disability and economics. The purpose of that book is to somehow bridge the language between economists and advocates. I am a rationalist economist and I know that that's a dirty word in many places in the sense that I use the techniques of economics and believe that the market is usually good at producing efficiently growth in the material products - apples, oranges, et cetera. I'm not necessarily a market economist on everything, however. I do think that sometimes there is market failure.

In particular, insofar as disability is concerned, one critical issue that I've tried to focus on, that I'm focusing on in my book, is to show that in fact all the traditional, rational economics market failures apply to people with disabilities; people with impairments, I should say. I've spoken to a number of my colleagues as to whether any class of consumers is affected in each aspect of the traditional rational economics market failures, and we haven't been able to come up with any; so that people with impairments, basically they face monopoly, they face - these are the technical issues, to some extent, which I've brought up to the Productivity Commission because I know there's lots of economists in there.

**MRS OWENS:** A whole gaggle.

**MS McKENZIE:** I'm a non-gaggle, if you like.

**DR FRISCH:** The traditional three or four market failures are where there are externalities, where people other than the direct consumers are affected, where there is monopoly and where markets break down. So I've shown that each of those happens to people with impairment.

**MRS OWENS:** And information asymmetry.

**DR FRISCH:** Yes. That's why markets break down. The purpose of showing this is to say that the market framework and how we define productivity is not clear. In my submission I think I've tried to point out that there's plenty of grounds for particularly Nobel Prize winner Amartya Sen - a lot of his work has been to show that, look, the aggregation, the GNP, the gross national product figures, et cetera, really don't make sense. There are enormous technical issues with that. The utilitarian materialist view is a very narrow view. It's a very particular view. So rational economics doesn't say that the market is always right.

That's the purpose of a lot of, you know, last week's introductory stuff. I must say that I'm in a bit of a bind as to how to present this because I need to - I'm writing a book and the book is meant to be for both policy-makers and advocates rather than academics, but yet I'm still trying to stay within a technical, economics academic ground, you know, of policy - how to weigh all that up. Anyway, that's by way of an introduction.

As far as the DDA is concerned, I think there are one or two major issues I'd like to highlight, because a lot of what I wrote last week was theoretical. The main highlight I think is that the enforcement mechanism for the DDA rests solely on complaints. I think I've tried to show that that is an ineffective, inefficient way. I think I've tried to show why. You asked the question before, why people don't make complaints? I think there are very rational grounds for people not to make complaints. The unjustifiable hardship clause in the first place is so ambiguous that it makes the law quite inefficient. When I use the word "inefficient" I'm using a particular jargon of economics.

There was another Nobel Prize winner, Ronald Coase, who said that if you don't have large transactions costs people will work things out amongst themselves, so long as property rights and the law are well defined. If the law is not well defined, then you get all sorts of ad hoc problems and inefficiency and externalities, namely bad things happen. Right? Externalities are created. People are affected. A lot of resources are spent on trying to clean up the mess as a result of bad law, uncertain law.

The unjustifiable hardship clause I really think makes the whole DDA quite ineffective, inefficient, because of its ambiguity. No-one knows what it means. I've been involved as an advocate in my local area. People trying to get a grip on what it means - and that creates so much uncertainty that it makes it inefficient. So that's number 1. Secondly - - -

**MRS OWENS:** Could we stop there just for a minute, because it might be easier to stop as we go, so long as you don't lose your train of thought.

**DR FRISCH:** No.

**MRS OWENS:** So you're up to secondly. With unjustifiable hardship, when we talked to HREOC the other day they said, "Well, it is really fairly clear" - and there are others who have made this point too, but not many - "because you've got a lot of case law there." So it's clear in the context if it gets through to Federal Court there is this case law which makes it clear how it's been interpreted on an individual basis. I said at the time, "Well, you've got a problem that a lot of people, potential

complainants out there, and even some advocacy organisations where there's non-legal people, are not necessarily going to understand case law and are not going to understand how that potentially could pan out in a court, because it's that information will not make a lot of sense to them and they wouldn't know where to even start looking for it." Any comments on that?

**DR FRISCH:** I concur with what you're saying. I'm not sure that I agree that there is a lot of case law. I think there may be a lot of case law in education and employment but not in the other areas and I think the reason that you have more case law in education and employment is because the potential benefit to a complainant of a complaint in education - we're talking about income, so that when a person is discriminated against in their future income - ie, education - or in their current income, in employment discrimination, the cost to them is very high of the discrimination. Therefore, there is going to be a net benefit to making a complaint because if I win I will get employed, my child will get educated, income - the net benefits are great, so the cost of making the complaint is not so great, relatively.

However, when it comes to the other aspects, namely access to buildings, access to communications, et cetera, all the little bits of discrimination, they don't really add up to much. Are you really going to make a complaint about not being able to get into a nightclub? Not really, because the cost of making that complaint is going to be fairly high and the benefit of the individual complaint for that one individual - well, you know, what is it? Not very much.

**MS McKENZIE:** But the truth is, however, that there are numerous cases about people who do complain about not getting into nightclubs, not being allowed into hotels. I wonder whether there's something extra which makes people complain, apart from the fact that they want some monetary outcome from their complaint? Sometimes I think it may be that they want some kind of vindication, not necessarily monetary vindication.

**DR FRISCH:** You're absolutely right. Yes.

**MS McKENZIE:** I just think it's an oversimplification, perhaps.

**DR FRISCH:** Yes. You're absolutely right, it is a simplification. I'm not sure that policy should be based on heroes as - you know, these are people who either are making a complaint as a matter of principle or on behalf of others. There's something extra. That's fine, you know, and I myself have made plenty of complaints or moved towards making complaints or threatened complaints on behalf of my daughter, where certainly the monetary value was not there. However, one of the reasons I've been able to do that and that the other people perhaps do that is (1) that they have the ability to do that, they have the social motivation, they have

something extra. I don't think that it's fair or efficient to really depend on that.

For a person who's actually making, who's earning a high income and who's - you know, life's tough enough than to be having to go and make complaints over what are considered small things in the individual case. One of the issues for me as an economist is, well, if the benefit is really not that great and the cost is great, then from a social point of view if the cost is great and the benefit is not then it shouldn't happen. However, when we're talking about many of these things, it's a lot of people. If you aggregate the benefits, then there is a case for a complaint. Many times I think people with impairments go through and they just accommodate to the situation and forget that they can't get in there.

Just this morning coming in here, there at the Citigroup House. We parked at Citicorp, which - you know that was for convenience, et cetera, which I'm not sure that I would have done and paid the high price if I could have quickly walked without all the barriers that are between here and Hyde Park and parking there. Then just coming across the road I noticed two coffee houses, newly-built buildings, in which there were just sufficient steps to be able to not have gone - would not have been able to get in there. You let it go.

So I think that a person with an impairment, people with impairments face these things many times a day and just pass them, don't make a complaint; so with each individual not making a complaint, and with all the individuals trying to get to a particular location also not aggregating their benefits, the number of complaints, potential complaints, is insignificant, negligible - sorry, the number of potential complaints is infinite compared to the actual number of complaints that do occur and I am suggesting that that's because the benefit-cost analysis for the individual and the whole DDA depends on complaints by an individual.

**MRS OWENS:** But as Cate says there are tangible benefits and intangible benefits and possibly some people weigh those intangible benefits more than others and are prepared to push along with it.

**DR FRISCH:** Yes, but they're the heroes of our society and, really, I don't think one should make policy only on heroes.

**MRS OWENS:** Sorry, that was a big distraction from unjustifiable hardship and you were just about to go on to number 2.

**DR FRISCH:** Can I - - -

**MS McKENZIE:** Yes, finish what you want to tell us about the complaints basis; how to fix what, I would have thought you might agree, is a problem.

**DR FRISCH:** Well, certainly with the Environmental Protection Act you do have people and consumer - the ACCC when we have monopolies - there are organisations out there which take priorities and enforce consumer law, enforce environmental law through various regulatory agencies. Now, I think it would be an enormous task to - like there's an enormous amount of social fixing to be done, priorities would have to be taken, but that's the way Alan Fels works - - -

**MRS OWENS:** Worked.

**DR FRISCH:** Worked - and that's the nature of some of these bodies. So I believe that an enforcement mechanism along those lines to complement the complaint system would be something that would enhance the rights of people with impairments and disability.

**MRS OWENS:** Someone suggested that HREOC could initiate complaints as one approach.

**MS McKENZIE:** Systemic ones.

**MRS OWENS:** Systemic complaints - or that advocacy and other organisations be resourced adequately to bring a complaint which could be a more systemic complaint.

**DR FRISCH:** Yes, they're all ways. Yes, they're all methods. I'm not sure that advocacy organisations - yes, I think advocacy organisations already actually have the power to make class action complaints. They don't have the resources, as you say. The resource issue - I'm not sure - one can never be sure as to how those resources are going to be spent and when an advocacy organisation, they're getting more money - I'm sometimes not sure how efficient they are. They often become bureaucratised and so I'm not sure sometimes about whether that's the way to go.

Whether HREOC can lodge the complaints - I'm not saying that it's something to be negated but it's something to be careful about - similarly with HREOC I think the power - they might have the power to do it already to - - -

**MRS OWENS:** No, they don't do it.

**MS McKENZIE:** They used to.

**DR FRISCH:** They used to, right. Well, you know, it was taken away - I don't know why, and I think that would be a good method but, you know, I'm never sure - I take a critical approach from outside - I'm not sure ever how things can be fixed up.

There's always problems. You know, I do believe that there's market failure and bureaucratic failure and political failure and all of these can be analysed. I generally do analyse them and try to understand why they're happening and I can generally find that there will be faults in all systems and there's good things in all systems. I don't have a view as to the best way to proceed but I do know that the current system is not working.

**MS McKENZIE:** Yes, to go back to unjustifiable hardship, did you want to add to it?

**DR FRISCH:** Well, no, just the ambiguity of the unjustifiable hardship and then the cost-benefit of individual - the other thing which I would like to perhaps address is the political failure. I think I've addressed market failure and I don't want to go into that here because it's very technical. The political failure I want to go into a little bit more because most people who understand the market failure then hope for political redress and I think we had in the submission before the lack of political will and I think the economist's approach or the rational economist's approach to understanding politics is to say, "Well, look what is everybody's interest here?" and I'm persuaded by the view that politicians seek to win the votes of what is called the median voter. They'd seek to get 50 per cent plus one votes in the 50 per cent plus one of the electorates.

Now, you never know who's that median voter and you never - you know, that's what the political entrepreneurialism is about, is listening and trying to find out who that median voter is in the median electorate - but what I do suspect and what I think is very important is that people with impairments are a margin. They're marginalised. Their voice is not heard because they are heterogenous. While people with impairments make up 20 per cent of the population, there are so many different types of impairments and so many different types of needs. We have chemical sensitivity. We have visual impairment, audio impairment, physical impairment, et cetera, et cetera, and the accommodation required in each case, each impairment is really quite marginal and the needs, the political demand, is marginalised.

It's of no concern to the person, to that so-called median voter in the median electorate, and so therefore of little concern to the politician and therefore of little concern to the bureaucrat and so that's why we don't have the political will. The median voter is concerned about little class education prices, GST, tax rates, mortgages, et cetera, and not about hearing loops and desensitised paints, et cetera, et cetera, and that's a real problem. So one on one, when you look the politician in the eye, they will absolutely relate to you but when it comes to making policy it goes nowhere and that I think is a real problem.

Similarly then, if you look at the interests of the bureaucrats, well, the

bureaucrat's interests under the economic - economists sort of try to see, well, what everyone's interests and the bureaucrat's interest is, "Well, minimise risk, follow the political leader of the day," et cetera. So if you are trying to minimise risk, well, you'll only actually take those risks when you see that you actually have done something awful. Then when one of your teachers does put one of those markers in front of a child with chemical sensitivity to test whether they really are sensitive, then they know they have done wrong and then it will be one - what was your phrase - "Yes, ma'am, no ma'am, three bags full." Then they will do it because that's how they are going to minimise their risk.

But the rest of the time they'll throw it back to you completely separate from disability; got nothing to do with impairment. A few weeks ago one of my daughters became sick. One of my daughters became sick at the local - they'd gone out for a meeting, a sort of Sunday night youth group thing, and a number of the kids became sick and over the Web they'd missed - you know, my own daughter vomited four or five times, had to get sent home from school and it happened to a few of the kids at the school. They worked out on the web site that what was common to them is they all had schnitzel. Okay? So I rang the restaurant to tell them that this is what happened and, "I'm ringing you tonight and tomorrow I'll ring the Health Department - - -"

**MS McKENZIE:** This is now going into our public transcript so the restaurant will - - -

**DR FRISCH:** Okay, well, I'm not going to tell you the restaurant's name. But the point I want to make is that the immediate reaction of the restaurant was denial. That's the point I'm making here because that's what happens at the school too. The immediate reaction of the human being it seems to be when faced with a problem is to deny it; second, is to put it back on to the consumers' faults, et cetera, et cetera. So this is why we need a DDA which is really effective in the same way that the person couldn't deny once it went to the - you know, these were the facts - but if there hadn't have been a Health Department official to whom I could complain and if there hadn't have been a Health Department official who could then check out the results and then enforce, then nothing would have happened.

Now, that's the case by and large in the DDA. You don't have that same sort of enforcement mechanism. That's the point I've got to through the anecdote with my youngest child. So they're the points I want to make: You know, the political failure; economic failure; the ambiguity of the unjustifiable hardship clause and the failure of enforcement of the DDA because it's only a complaints based system.

**MS McKENZIE:** Can I just go back to unjustifiable hardship for a minute. I'm going to ask you a question which I suspect I might know what your answer is going

to be and my question is a bit similar to the complaints commission which is if you recognise that it's a problem with the unjustifiable hardship concept, how should we fix it? I suspect you might be going to tell me you analyse the circumstances of raised difficulties but you're not suggesting a solution but have you got any thoughts?

**DR FRISCH:** I do actually. I think that the social cost-benefit analytics of economics does provide a mechanism. I'm not sure - I've been thinking about this a lot. I think a computer program which enables an individual complainant, if you put in the right parameters, to get a bit of a sense as to whether they've got a case or not could be made. I've been thinking about how - and I do have an example for one of my classes in which I do this cost-benefit analysis and it will make it into the book, but it didn't make it into the submission here today because there are still a few problems with it. But I believe that a computer program going onto the web site which says, well, if the person was truthful or if they can seek some advice from someone in HREOC, with some help as to how to fill this in" and it can be done by telephone, whereby, "Well, this is what happened to me. This is the situation" et cetera - so whether there is a social cost benefit or not.

The second point then is whether the individual who is - the individual defendant - what is going to be an unjustifiable hardship to them. That's a tough one, because we don't really - the act is not clear as to how much of the burden-shifting is acceptable. For example, in the case of a nightclub that has to put in a ramp, and it will cost them - - -

**MS McKENZIE:** This is the example in the submission.

**DR FRISCH:** This is the example in the submission. I think the way the case law, et cetera, and the act goes at the moment, it implies that the nightclub operator will bear the burden of the cost, and that's not clear. It might go to the landlord, it might go to the consumer - it can be shifted. Now, we need some guidance as to what is permissible there. We need some guidance in the act, I believe, as to what percentages are or are not your thresholds - you know: what are we going to be talking about? Is it financial liquidity cost or is it economic burden, or what is it? They're the issues which I think can be brought up.

Not simple questions at all, and I'm actually looking for someone in our own university, in the accounting department, to help me with working out what balance sheet or profit and loss numbers can be used here. How can we actually identify this - clearly not in the act, but in regulatory or in some sort of annexes, to give some sort of feedback of, "Do I have a case here or not?" So that's the direction of my thinking at the moment - no, it's not at the moment. I'm sure that's going to stay the direction of my thinking. How it's going to resolve itself, I don't know.

**MS McKENZIE:** But in your view, the unjustifiable hardship concept should be analysed in economic terms?

**DR FRISCH:** Yes.

**MS McKENZIE:** That's the bottom line of what you're saying.

**DR FRISCH:** That's the bottom line, yes - so in economic terms rather than in financial terms. There's a very clear distinction in economics between financial burden and economic burden, and it should be economic. It's very difficult to define that, because when we talk about "economic", economic cost is really the cost of the next best alternative, which no-one really knows what the next best alternative is sometimes; it involves art and judgment, and that is all a bit up in the air as to how a court can deal with that.

**MS McKENZIE:** I have to say, given the cases, I don't think that that's an argument that would be necessarily thrown out by a court. I think the concept is so widely criticised for its vagueness, that the very vagueness may in some ways help you to make arguments about what should be taken to account in relation to the concept.

**DR FRISCH:** I'm not a lawyer; I don't know.

**MS McKENZIE:** Well, I'm speaking as one.

**DR FRISCH:** Right. Okay.

**MS McKENZIE:** As I say, I don't I think it's an argument that the case law would throw out.

**MRS OWENS:** You've touched, Jack, on a really more fundamental issue in what you just said then, and that was about the nightclub and who should bear the burden: should it be the operator or should it be the landlord; should it be the consumer. But there is a broader question about who should pay for adjustments which potentially can benefit a wide range of people, and whether there is a broader community responsibility - I mean, how do we divide up this responsibility? Have you thought about that one?

**DR FRISCH:** I certainly have.

**MRS OWENS:** I knew you would have.

**DR FRISCH:** That's almost a dorothy dixer. I guess this is where the argument on

asymmetric information - that I put forward in the case. There is no market, and there can be no market, for offsetting the financial cost of an impairment. The reason there cannot be a market, and never will be a market, is because the insurance - I've made the case in here theoretically, but I guess the best way to look at it is to look at the current state of our health insurance. Health insurance and unemployment insurance - well, unemployment insurance - we don't have private unemployment insurance because a private market would not have it, because of the asymmetric information.

Now, we do have a private market in health insurance, but it is in continual crisis, and I teach my students that it will always be in continual crisis because of the asymmetric information problem, namely, the insurer will always be insuring a cohort which exists, and people - the consumer, only those consumers will buy private insurance who find that it's worthwhile to buy it, which means that those people who find that the premium is too high will drop out, which means you're going to get a less healthy cohort insuring privately, et cetera, so we have to provide subsidies, et cetera.

Now, this is the case with long-term permanent impairment as well. The market has broken down, there is no market, and so as a result people with impairments bear all the financial cost, bar things like your disability support pension which offsets some of this, bar some public facilities which decrease the cost, so that if you have a public transport system which is accessible, then you no longer have to catch taxis. If you have supports, then the cost decreases to some extent. So therefore, in much the same way that society bears, through taxes, the cost of unemployment insurance and a large part of the cost of health insurance as well, so we pay subsidies to consumers to take up private health insurance - something which both parties implicitly agree with, because even though some people in the Labor Party rail against it, they actually haven't made a policy decision against it, because they know that you've got to maintain the private health insurance somehow, and subsidies is the way.

One area which they have not, which society doesn't really get involved in supporting, is long-term permanent impairment, and so I do believe that society would be willing to pay, that it is society's obligation. Some rough back-of-the-envelope estimates I've made - I don't know whether I'm kidding myself, but I don't think it would be too - I don't think I'm exaggerating in saying that I would expect that the average additional cost of living to a person with an impairment would probably be up around four or five thousand dollars per year - just rough.

**MRS OWENS:** It depends on the impairment.

**DR FRISCH:** It depends on the impairment, yes. Yes, I know. People who are extremely impaired, at one end I don't think it would be difficult to say it's up to 20 to 25 thousand whereas - - -

**MS McKENZIE:** You're looking at average cost?

**DR FRISCH:** I don't know. If you take everything into account - and I've done these sorts of measures and I've made submissions to the McClure Report a few years ago - it's enormously difficult to measure, because there's underestimates, overestimates, all sorts of things. But let's say that's the case. If we spread the cost over the 17 million people in Australia, that cost, it really wouldn't come to much per person.

You know, if we take \$4000 per - and say that that \$4000 is to the class of people - of that 20 per cent. Let's only talk about the 5 per cent with the greatest needs, we're really spreading \$4000 for 5 per cent over the other 95 per cent; it brings it right back down. It would be the implicit premium, and I think there is a case for the citizen to pay, because the citizen, if they knew what the cost was if they were to develop an impairment, or their child develop an impairment, or their friend develop an impairment, then they would be willing to pay that, I think.

**MRS OWENS:** That changes perceptions. Coming back to your additional cost, what are you talking about as being additional? This is additional net of health expenditures because there's Medicare; net of ancillary insurance? Because you can insure for some additional costs through ancillary insurance.

**DR FRISCH:** Yes.

**MRS OWENS:** So there is a market there for some devices and so on.

**DR FRISCH:** Yes.

**MS McKENZIE:** But not against a limited - - -

**DR FRISCH:** Well, some devices, if you're poor enough then you get PADP and you get home care, et cetera, which this then impacts - if you're poor enough, you do get some direct services; no question about that. They're usually inadequate, they're usually pretty lousy service, it's on an ad hoc basis, it goes to the person who is most articulate and shouts the loudest, et cetera; not a very efficient way of doing things.

This "poor enough", the provision of these services of course provides a greater than 100 per cent implicit tax rate to employment participation, which is something I would love the Productivity Commission to address in light of the McClure Report

and that whole interaction. I haven't even mentioned the totality and the holistic nature and the inefficiencies across the state, federal, departmental lines. That's another question again.

**MRS OWENS:** There's a whole other inquiry or two or three.

**MS McKENZIE:** Yes. That's another inquiry.

**DR FRISCH:** Yes. But it certainly relates to disability, I think - no, I'm sure. So let me just go back to that point. Where I talk about the additional costs, what are they? I could get personal here. I'll get a little bit personal, but let's say today - today I've already paid \$25 more than I would have otherwise paid by going to the parking lot because I came with my daughter rather than came alone. So that's \$25 already. That's an additional cost, purely due to the impairment.

If I hadn't have come with my daughter - which I thought would be a good thing - I would have parked down by the Domain, would have crossed quickly across the Domain, got here in 10 minutes, and bang, bang. Instead, well, I wasn't sure what the path was going to be like from the Domain, how much longer it would take getting back, so instead I paid downstairs at the parking lot. So that's one thing. There are therapy costs, there are physiotherapy costs, which don't get reimbursed. There are additional costs to having to - well, transportation.

**MRS OWENS:** Adapted your house.

**DR FRISCH:** Yes, adaptations. When one goes out one has to manage things. One has to ring ahead to find out whether this place is accessible or not accessible, and then find out from three or four - but all of that is a cost in time, as well as a financial burden. So a large part of this is really there's a time cost, and that's the externalities not only to the person - that is an economic cost, the time cost - the extra time having to go around the long way to finding, to managing the system.

Let's go back to the additional costs. Probably you would need a mobile phone where other people might not, although now everybody has got a mobile phone, in order to maintain communication, so this is an extra cost. There are the extra costs of schooling issues; they are the ones that I'm involved in.

**MS McKENZIE:** But these additional costs assume that things are as they are. In other words, you are not adding into those costs some estimate of the costs that it might need, for example, to make all of the school that the child is going to attend accessible.

**DR FRISCH:** No.

**MS McKENZIE:** Basically this is on the assumption that things are as they are.

**MRS OWENS:** These are your private costs?

**DR FRISCH:** These are the private costs, yes. Yes, these are the private costs. At the moment they are basically borne through extra time taken and through extra adaptations and having to adapt to the system because it is not a seamless free path of travel in our case, whether that's physical disabilities - similarly with people with visual impairments, I expect. It's not a seamless path. You have got to do extra things. You've got to find Braille machines; you've got to convert things, et cetera; you've got to find ways around - other ways of doing things. And that's all extra cost to the person.

**MRS OWENS:** Come back to this insurance market. There is no insurance market to cover these sorts of costs.

**DR FRISCH:** No, and there never can be.

**MRS OWENS:** Because of the moral hazard and so on.

**DR FRISCH:** Yes.

**MRS OWENS:** But you just mentioned private health insurance before, and you've got a very skewed market there. We did an inquiry a few years ago on private health insurance, as you probably know. So there is a high level of government regulation and support in that industry. Is there a potential to set up a similar sort of - well, maybe not private health insurance but we do have a Medicare arrangement.

**DR FRISCH:** I don't know. That's where the DDA comes in. I don't think that's the system we need because the transaction costs would be so high. When we are talking about health and medical insurance I think the transaction costs are not that high. We have a system of doctors who are trained, et cetera. To actually train and educate people in the social security system or some other form of organisation to all of the different permutations and combinations and problems that may require some reimbursement to an individual, and to test that, it would be a nightmare. I think the transaction costs would be too high.

So therefore, I should make this point - and I've got it here as the last - I think the strength of the DDA potentially is that transaction costs are minimised. And this is sort of my own - the way I teach economics, actually. In economics - when I was a student we used to teach economics as - the question was really, "Is it government or is it private sector?" et cetera, and its demand curves and supply curves. To me, I

think that the institution or the organisation that ought to do something is that organisation or system or institutional structure which minimises transaction costs. And this is following the work of Ronald Coase, of whom I mentioned before and of whom I'm a - you know, the two economists that I hold in greatest esteem are Amartya Sen, on the one hand, and the other is Ronald Coase.

Incidentally, Ronald Coase wrote his article in 1927 and it sat in the journals for about 60 years because no-one really understood it. But what he was saying was, "Have the type of organisation which minimises transaction costs." And I believe that the DDA potentially is the place and the system which will minimise transaction costs, complemented by a real enforcement system under HREOC. So if you had an effective DDA with effective enforcement, then I think that is the way that the lives of people with impairments, and the additional costs faced by people with impairments, would be minimised.

**MS McKENZIE:** Rather than doing it through some insurance scheme or some tax system scheme.

**DR FRISCH:** No, I think it would be impossible. The transaction costs would be - it would be madness. And maybe it's my failure of imagination but I really think the DDA potentially is at the moment - I bemoan the fact that it is weak and I really wish that it would become stronger. It makes economic sense and productivity sense - it's one element of the whole productivity issue which would be sensible, to make it stronger.

**MS McKENZIE:** What you said is not a realistic possibility, but even if one was somehow to develop a scheme for insuring against the additional costs of disability, that still only is looking at primary costs, it's not looking at the other side of the equation, which is what happens in society, what the employer does, what the service provider does, what the builder does.

**DR FRISCH:** No. That's right, yes. No, it wouldn't. Correct.

**MS McKENZIE:** That's right.

**MRS OWENS:** Although could you have an insurance market for employers and education institutions and so on.

**MS McKENZIE:** Which would insure the costs of making reasonable adjustments.

**MRS OWENS:** Lloyds say that they insure all sorts of peculiar things. There's an article about them in today's Sydney Morning Herald, about how Lloyds of London have insured all sorts of odd things over the years.

**DR FRISCH:** Aren't they also going broke?

**MS McKENZIE:** I don't know whether the (indistinct) might be happy about that.

**DR FRISCH:** That's right. I was going to say, aren't they also going broke?

**MRS OWENS:** No. Well, actually they have just turned it around. Lord somebody has just got it back into profit this year. That was what the article was about.

**MS McKENZIE:** Let's ask again next year.

**DR FRISCH:** Yes. It's up to the vagaries of how they invest. We see that insurance markets often need governments to bail them out as well, so you need reinsurance markets, and ultimately reinsurance markets need government. Government is very important. The other thrust of my teaching in economics, especially because we have so many students from overseas in our masters classes, is to show that, "Look, a lot of the stuff" - this is in my last lecture - "I've taught here really is preconditioned on a stable, secure, political infrastructure, reasonable laws, no corruption, et cetera."

My last lecture of the semester is usually on the importance of government providing a framework of good laws, of having a system of security, et cetera. I sort of point out to them that, "None of this applies if you don't have that political infrastructure and social cohesion. And that's why the countries that (indistinct) come from are poor in many cases." So I think there is a role, ultimately, and the DDA - I really come back to that - is a very important piece of legislation.

**MS McKENZIE:** Just to go back for a second to Helen's query about insurance, what you are really saying is that's not a viable alternative.

**DR FRISCH:** No, I don't think so. It's my judgment that it's not, and my judgment is that it really sits with the DDA is the alternative - - -

**MS McKENZIE:** The most viable.

**DR FRISCH:** The minimum transaction costs system.

**MRS OWENS:** Because ultimately the DDA is going to at least reduce some of those costs.

**DR FRISCH:** Offset - that's right.

**MS McKENZIE:** Yes.

**DR FRISCH:** It will mean that we don't have to really park across the road, we can come by train. It means that you will get the job. You are more likely to get a job because you will be able to get to the job on time, with certainty, knowing that there are - and I'm talking about physical disability now because that's probably the area that I understand best - you know, that there will be a ramp into the building and that the lift will work. Sometimes, of course, it doesn't; things do break down. You can't guarantee certainty in everything but you will be able to do it without having to make special arrangements that always cost, either financially or in terms of time.

**MRS OWENS:** Can I clarify another point, which is really going back about three steps, when you were talking about market failure. By the way, in your initial comments you said something about market economists, that you are not a market economist on everything because you believe that there are things like market failures. I think most market economists accept there are market failures as well.

**DR FRISCH:** Yes. Politically they don't though. The politicians have taken up the rhetoric that the market does everything.

**MRS OWENS:** We certainly recognise that there's market failures.

**DR FRISCH:** I know the productivity - yes, I know.

**MRS OWENS:** I was just going to clarify something, and that was in relation to natural monopolies. You talked about natural monopolies in providing goods and services for people with disabilities, and I was just wondering about that. Why are you suggesting that these providers are natural monopolies? I mean, you can always import things from elsewhere. What are you exactly saying there? What are the natural monopolies?

**DR FRISCH:** I think the natural monopoly is that the market is small for each particular product.

**MRS OWENS:** But we've got globalisation.

**MS McKENZIE:** The markets are small, even elsewhere in the world. That's the problem I suppose.

**DR FRISCH:** Well, you are right. For some products probably that might be the case but again, coming back to physical disability, in a wheelchair, yes, much of the componentry is imported but there always needs to be some very important

adjustments to be made because the wheelchair - the heterogeneity of the impairment means that each person has a certain - the seating, the back - the seating needs to be adapted. The handrail needs - the armrest has to be adjusted, et cetera, and each of those requires special componentry, some special modification which adds to the cost. You're right. With globalisation, if you import a lot of these things, they're possibly - the US market is big. I'm not sure that it's big - - -

**MS McKENZIE:** It's not huge.

**DR FRISCH:** It's not huge.

**MS McKENZIE:** It's big though.

**DR FRISCH:** It's not as big as the market for mobile phones. That's where we really get the economy. I expect that even with wheelchairs we're still talking - even within the US market we're probably still talking about the downward sloping part of the cost curve in the US.

**MRS OWENS:** But you're not talking about just one supplier of wheelchairs.

**DR FRISCH:** No.

**MRS OWENS:** I take your point about adapting these things, but you say in your first submission to us that they're often natural monopolies, and I'm really just trying to pin down to what extent that may be a bit of an overstatement, because a lot of goods and services are provided to people with all sorts of disabilities. I just find it difficult to accept that there are often natural monopolies.

**DR FRISCH:** You're right. It's something to research and something to look at. I'm not sure. Again, as I say, this is the beginnings of my book and there are a lot of questions raised in there and the one you raise is a question for inquiry and research.

**MRS OWENS:** I think it would be a very interesting research topic, to pin down where there are natural monopolies and where people are able to access products which are from a range of sources. Just because there's one supplier in one market in Australia doesn't necessarily mean that people are required to just go to that supplier.

**DR FRISCH:** Yes.

**MS McKENZIE:** The one other thing of course one has to build in is if you're accessing something from overseas and accessing something here it's not necessarily equivalent. There are not just additional costs for transport but often it's just simply harder to do.

**MRS OWENS:** Or there may be standards that are required here and so we have to meet - - -

**MS McKENZIE:** You may well need retrofitting here to meet our standards. That's another matter.

**MRS OWENS:** So it depends whether you're talking about wheelchairs or other goods and services but it would be a very interesting - - -

**DR FRISCH:** I agree. I probably did overstate that. But let me just say, looking at the cost, I do wonder why things are so much more expensive. That's how this came up, because a lot of this stuff that - I think about it and I think, "This doesn't make sense. This is the cost almost of a car." It's not a car. It doesn't go as fast. Yes, there are other safety mechanisms. Cars have got to be safe. So I think to myself, "Why is this thing \$12,000 and I can buy a car for 18 which is bigger and got a lot more luggage?" et cetera, and the only answer I come up with is that we're still going on the downward slope of the cost curve here and the market is not big enough. That's just in my own mind and, you're right, it's something to research.

**MRS OWENS:** I'm just thinking of other private costs. I don't know whether you've got one of those lift things in the back of your car to get the wheelchair in, and all those things add to the costs.

**DR FRISCH:** Yes, the height of the car - - -

**MRS OWENS:** Then you have to have a special sort of car. You've got to have a bigger car.

**DR FRISCH:** It's interesting because you asked me the question, and this is one of the things in what I wrote to the McClure Report - was that you internalise the cost and if you were to be asked what the costs - they become part of life and you forget about them and it's only - and this is me, and I've written on this extensively and you asked me the question, and I was flabbergasted. I was thrown. Yet if I had my submission, I've got a whole page of things that I've been - and you just brought up to me: the ramp with the hydraulic lift to the car, which I've forgotten, and the extra cost of the car. Put it aside. It's internalised. It's now part of life.

**MRS OWENS:** No, I didn't mean to ambush you there.

**DR FRISCH:** No, that's fine.

**MRS OWENS:** It will be very nice to see your submission to McClure if it's

possible to get that. I don't know whether you've sent it to our team.

**DR FRISCH:** No, I haven't. It's on my web site, but I can do so.

**MS McKENZIE:** We can get it off the web site.

**MRS OWENS:** Fine. We'll take it from there. We can get it off your web site. It just sounds like there might be some other interesting material in there.

**DR FRISCH:** I talked about the 100 per cent tax rate because of PDHP and I've got other stuff on the cost of disability.

**MRS OWENS:** Just one last question from me. Do you want to clarify or talk a little about what you might see to be an economic measure of the effectiveness of the DDA? Just a little question.

**DR FRISCH:** I think the employment participation - no, not employment participation, participation measures; actual results - I think it's going to be a long time coming. I don't think that it's fair - the DDA has been around for 20 years.

**MRS OWENS:** 10.

**DR FRISCH:** 10, sorry. Even 20 is not going to be long enough because of the holistic network, the interrelationship with everything. The classic example that I give is that the value of accessible buildings is zero - no value to having accessible ramps on every building if you can't get to the buildings because the transport system is inaccessible. Likewise, the value of an accessible transport system is zero - no value; no-one's going to use it if there's nowhere to go to because all the buildings are inaccessible.

That's an extreme case, of course, but the interrelationship highlights that it all sits together. Not only building and transport is the obvious case but that also, related to that, is infrastructure of service support, of employment support, employment participation. So the whole gamut needs to integrate before people will actually start using all the facilities seamlessly.

**MRS OWENS:** You can't get your participation better until you've got - - -

**DR FRISCH:** You can't get the participation measure, so it's going to increase very slowly.

**MRS OWENS:** Yes.

**DR FRISCH:** Coming back to the transport system, the transport system became pretty good during the Olympic Games but just a breakdown in one node is enough to break the whole system, in that you might be able to get onto the train and you've got lifts in both systems - both ends - but if you don't know whether the lift at the other end is broken down or not, if you can't get information as to whether it's working or not, there's going to be a sense of insecurity as to whether to use that system.

We used the transport system during the Olympic Games here and a couple of times we had to go beyond our station and find ways around it, and things were working as well as they could during the Olympics but it still didn't all fall together. There was breakdown but that's life. That's the way it goes. I only point that out to show that a breakdown in one node in this whole gamut of interconnected disability problems is enough to slow down the increasing participation, but I believe that participation in the number or proportion of people who are not spending time - and this is a study by Michael Bitman showing that people with impairments by and large spent much too much time at home watching television. It's when they stop watching television and start going out to nightclubs, start going out to football matches, getting jobs and the employment participation rate increases, that's when we can start seeing that the DDA has worked.

**MRS OWENS:** Thank you. I think that's really a good place to stop. Sorry, are there any other points?

**DR FRISCH:** No, that's fine. Thank you very much.

**MRS OWENS:** I did warn you we might go over time.

**DR FRISCH:** Yes.

**MRS OWENS:** Thank you very much indeed.

**MS McKENZIE:** Thank you very much.

**DR FRISCH:** Thank you.

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**MRS OWENS:** The next participant this morning is Melinda Jones. Welcome, Melinda, and thank you for your - we've got a draft submission at this stage. Could you please repeat your name and the capacity in which you're appearing, for the transcript.

**MS JONES:** Thank you, Helen. My name is Melinda Jones. I'm here in my private capacity as a human rights scholar and disability advocate. I spent something like 25 years working at universities, most recently at the law faculty at University of New South Wales for the last 12 years or something. I have significant expertise in human rights generally, as well as disability and children's rights, which I've done a lot of work on, but also - and something that, as I said, I didn't realise how important it was before - is in administrative law. My case book is now in its fourth edition, and it's the textbook that's used all around Australia, and administrative law - one part of it is statutory interpretation. So I actually come to this as a human rights scholar, but with skills specifically in interpreting statutes.

**MRS OWENS:** And you have published very widely, with your co-author, Leanne Basser.

**MS JONES:** Yes. Leanne Basser and I work on a big project that we've called Law and the Social Construction of Disability. We also have another project on children's rights. But I also do other work in my own right that's independent; I actually have other collaborators as well. In particular, the theoretical background to my submission is my work on human rights theory. I did bring along some extra bits of paper, and I thought I should explain to you what it's all about. Cate, I'm sorry I didn't get this to you earlier, but I'm just going to talk to it.

**MS McKENZIE:** No, I'm not fussed.

**MRS OWENS:** Thank you. If you talk through it, I think that would be very useful.

**MS McKENZIE:** We might just ask you questions along the way, if you don't mind.

**MS JONES:** No. As we said, conversation is very nice. Look, I started what I've just given you today with what I've called an inclusion check list. The strategy for human rights that I have is if you want to make sure that you're really inclusive, you have to make sure you don't leave anybody or anything out. One way of going about that is by creating check lists of different sorts.

So my first check list is the type of disabilities - psychiatric, intellectual, physical, et cetera. I have included addiction and obesity on the list, and I'm sure

there are other things I haven't thought of. I didn't include HIV-AIDS. So it says, "Physical, intellectual, psychiatric, vision, hearing, behavioural, disfigurement, chronic illness, addiction and obesity" - that check list of types. I'll come back to talk about the social model and the medical model in a minute.

My second check list is additional characteristics, which are indigenous women, aged, children, people from non-English speaking backgrounds, sexuality, minority religion, race, ethnic origin. I then look at the different sorts of disempowerment in list three: stigma, discrimination, violence and abuse, exclusion and poverty, under which I had included unemployment, low education, homelessness, et cetera.

Then the fourth list is of sites of discrimination, places where discrimination or disempowerment might occur. Some of this list is more important than others, but I just said at the beginning we've got to think about private as well as public domains, and I think that's something that hasn't always been thought about, and I'll give you one example. The list though reads, "The legal system, the workplace, educational institutions, the economy" - and the financial institutions of the economy - "the social welfare system, family, religion, culture, political system, clubs and societies and leisure activities, transport, information access, physical access, communication, accommodation". Again, that list could be longer.

Now, the point to this list is that when you are coming to any conclusion about a particular matter that you've made a decision on, and you want to make sure your decision is fully inclusive, you need to check it. Does it work for all the different types of disability, and is it intended to - you know, works - so, really, that you want every provision to work for every type of disability. If you do, you have to think it through. Your strategy might be brilliant and it might work really well for indigenous people and children, but might not work at all for gay and lesbian women and men, and it may not work at all for people from non-English speaking backgrounds, or whatever. So it's just a check list to say how will this thing work.

The same thing about types of disempowerment. One of the things about disability discrimination law and the anti-discrimination law is, discrimination is only a small part of the picture of disempowerment, and there's a question about how we feel about that. Because we don't have a bill of rights, because we have no human rights legislation in this country, people refer to the Sex Discrimination Act, the Race Discrimination Act, and the Disability Discrimination Act as human rights instruments.

Now, if they're the only place where human rights is being protected and they're meant to be comprehensive - at least for those people whose lives they cover - then we actually have to go beyond just discrimination issues, and I think that's

something that really has to be - I think we have to be clear about what the objective of the act is, what we're trying to do with the act, and are we just trying to deal with discrimination or are we trying to look at exclusion?

My list of sites of discrimination again is just to try and be as thorough. You know, we might not have thought that religion might be an issue but there might be an issue to do with disability and religion that just hasn't come up, but when you're looking at a particular outcome you go and say, "Well, how does it fit with this sort of list?" So it's really a conceptual tool, which you may like or may not like, but I actually think - when I am writing I interrogate my own work according to these sorts of lists.

Now, the rest of the document is trying to distil the essence from my submission, if you like, having said that I'm interested in human rights, not just anti-discrimination. In my list I've got a list of urgent matters, and I've got them to do with the act, to do with HREOC and to do with competition, and then a list of things that aren't so important but of course are important, and then throughout my submission there will be a lot of other points about various things that you may take or leave, obviously, as you wish. Would you like me to keep on going?

**MRS OWENS:** Please go on.

**MS JONES:** Okay. I think the most important thing that has to be emphasised is that the DDA must be retained and its current structure must be retained. As a piece of human rights legislation, although we've got the issues about just discrimination, it has the possibility - well, it is, I think, the best piece of legislation in the world, without any question; vastly superior to the ADA, vastly superior to the British DDA, and to all the other places that have modelled it, for a number of reasons.

One of the reasons is its structure. In the Melbourne University Law Journal article that Leanne and I wrote last year we talked about operationalising human rights, using the DDA as a model. One aspect of operationalising human rights is to ask the question, "Whose problem is it?" With disability, one answer to the problem is that it's the individual with the disability. That doesn't necessarily flow from the medical model - "I'm a person with a disability, there are barriers all around me. It's my responsibility to locate those barriers and do something about it." I don't think that would be very good as an outcome.

So your next possibility is the state. "Well, what is the state going to do? The state has to be a player. What is the state's responsibility in doing this?" Now, in the DDA the individual has the opportunity, through the complaints process, and of course by other ways, of participating. The state has responsibility with respect to HREOC as the institution that's administering it, and has responsibility with respect

to regulations and standards, whatever.

The third aspect though is the community. If we really want to change society - and the Disability Discrimination Act requires us to change society to a fairer society in which all people can equally participate - that was in the second reading speech by Brian Howe. He said specifically that the aim of this act was to achieve a fairer, inclusive society, a just society for all people, and that people with disabilities have the same rights and dignity and right to treatment as any other Australian. So we're not talking about something that is just for a small category of people with disability; we're talking about a picture of Australia.

Action plans and industry self-regulation both provide a way in which the broader community can be involved in owning the problems to do with disability disempowerment. So the structure of the act - although there are other problems - I think the act is still very good. If nothing happened to it, it would still be a good piece of legislation. I can't emphasise that enough. I would be very worried if, because action plans don't work, well, they were taken out, or whatever. So that's my fundamental starting point.

The second point is of urgency because of the current state of decision-making under complaints in the DDA. One of the things that makes the Australian legislation vastly superior to any other piece of disability discrimination legislation in the world is the definitions section. While people have complained about it being the medical model, I think they fail to understand something - it is definitely; it's got reflections, it talks about loss of things and impairment and whatever else, definitely relating to a medical condition of the individual.

But what the definitions section does is it basically says, "Look, we don't have to worry about whether the person has a disability who is bringing this action. We have to worry about whether the person has been discriminated against," and case after case in the States and in England are argued about whether the person has a disability, and they never get to the question about discrimination. Now, that is wrong on every possible level. It's wrong because it focuses on the abnormality of the individual, by its process.

Even if you have better words in your act that say "people with disabilities who are identified" or "qualified" or whatever it is, you might leave the medical list out. But if you spend all of your time debating whether someone is entitled to use the act, that's incredibly disempowering, it's an incredible waste of time and money, and it doesn't ever get to the point. A very high percentage of cases in the States are thrown out because the people don't meet the criteria.

The reason that the definition works the way it does is because technically the

definition is an inclusive definition, and that turns on the question of statutory interpretation. When you read an act and it says that you must have this, this, this and this in order to be able to use it, then that can be exclusive and closed. When you have "or" in the way you do, and the open-endedness, that's inclusive and what it means is that you can include anything that's of a like matter; so you don't really have to even go into detail if it's something unusual.

You know, the substance abuse cases was something unusual, but they didn't spend hours in the discussion about whether or not they could use the act. The question still related to the discrimination. Until recently, I would have said that on that point everything is wonderful and we actually should just leave it as it is. That might turn out still to be the case but I know that you know about the Purvis case, and I think it's impossible at this time - and maybe before you make your report there will be a High Court decision - but at the moment the Purvis case points to a problem in terms of the interpretation of the definition, and I also think it really points to the problem of what sort of model of disability you use. I assume that you're familiar with Purvis and I don't need to talk in much detail about that.

**MRS OWENS:** No.

**MS JONES:** The crucial thing is that in the Federal Court, where we're up to right now, a distinction has been drawn between disability and manifestation disability, and if you think about that, in this case they said the disability was an intellectual disability and whatever else, and the manifestation was behaviour. If you start thinking about that with other disabilities - someone who has a physical disability, one part of that is that they can't use their legs, say, and a manifestation of it might be using a wheelchair. On that basis you could say, "We're not discriminating against you. We like you a lot. We're just not going to let you in the building in that contraption. Leave the contraption outside and come in."

That is totally consistent with the dichotomy that's being drawn here. It's the same thing I was thinking as I came in. I have a very mild visual disability, that I can't see without glasses. The manifestation of that visual disability is the fact that I wear glasses. If you're going to say that there is a distinction between manifestation and the disability, what you've done is introduced into the legislation something that's not there and something that the court was trying to avoid.

Unfortunately, it's because we have the good lawyers who work in the area working in both sides of this case, and the job of a lawyer is to work for your client. If you destroy a piece of legislation along the way, that's fine. We've got lots of bits of legislation and social policy that have been destroyed by clever barristers throughout Australian history. It would have to take somebody very clever to think up this distinction. However, even if you read the HREOC judgment, the reason the

distinction came up jumped out at me right at the beginning of reading it because I knew about the problem before I read the case.

In the case, we're told that the young man in question had an intellectual disability, he had epilepsy, he had a visual problem and he had behavioural problems. But the behaviour was a result of his intellectual disability. It wasn't part of the intellectual disability; it was as a result of it. But not much later in Innes C's decision, he interviews a doctor about it, and what the doctor says is, "What was wrong with this child is an acquired brain injury." People who are on the medical model don't want you to say the grounds of disability is an acquired brain injury but if you think of his disability as acquired brain injury, then behaviour is automatically part of that picture in a way it's not so obviously if you're talking about intellectual disability.

Intellectual disability always has with it behaviour issues, but I suppose what I'm saying is that aberrant behaviour, really aberrant behaviour, is not really part of an intellectual disability and that is obviously the case with some people and obviously not the case in others, but you wouldn't be able to shear it off if the disability was thought of as acquired brain injury. This is ironic because, if you want to move forward in terms of legislation, you don't want the medical model of disability to be the one that dominates.

The medical model leaves the problem with the individual. It works on the fact that the individual has a deficit. It's an individual tragedy. The individual is abnormal in some way, and if you have to prove you're abnormal in order to get access to saying you don't want to be abnormal or you would have to prove you're abnormal in order to be treated like someone else, it's a bit strange, isn't it? So we go to the social model of disability. The social model of disability says that the problem with disability is not in the body, it's in the environment, and that the task is to work out all the barriers to inclusion.

That was radical in terms of thinking about it. It managed to move people away from being only thinking in terms of rehabilitation and welfare and started being able to talk in terms of rights, but it actually doesn't go far enough and it's the feminist scholars who have said, "Hey, we've spent years trying to have our bodies included in all the women's' literature about bodies and the social model wants to take the body out of the picture." But the reality is for anyone with a disability that there are both personal and societal manifestations and difficulties.

We need to go one step further as well, because you don't just have a right to not be discriminated against because you are a person with a disability, because there are barriers in society. You've got a right, independently of whether there are barriers in society and independent of whether you have a disability. The basic

proposition that I'm working from is that all people are entitled to be treated with equal dignity and respect; to be treated as ends in themselves, not as means to ends, and this is really where a human rights perspective comes in.

Barriers to inclusion is one part of the picture but it's only one of the parts on the human rights model. What you're asking is what are the things that happen to people that are disrespectful? What are the things that happen that show that they're less valued than other members of the community? Those things might be barriers but they might not be. They may be attitudinal, and I'm not sure how you remove an attitudinal barrier on the social model. On the human rights model you use human rights education, because the education deals with it not as a barrier, if you like, but as another strategy.

I've talked around in circles a bit but I actually think people make a mistake about thinking the social model is inherently bad. The social model is only inherently bad if you follow it with the values of individual rationality, commonsense contract-making competence. All of those terms - or incompetence, irrational - went alongside the social model but the values don't have to be there if you say, "One aspect of the condition is" whatever the manifestation. Language is very difficult in this area because you say something and you're going to insult somebody and, if your aim is to be respectful, I think it is a very difficult thing.

I think that you don't want everybody in the world necessarily to know what medical labels you have, but what you want is for the effect of those medical labels to not make it even more difficult. It's difficult enough being a person with a disability. You don't need all the other crap that goes with it as well. So the job of everybody - the community, the society, the state, individuals with disabilities and individuals without - is to actually focus on those questions. Would you like to ask me anything about that? I'm not sure how clear I've made that.

**MRS OWENS:** No, I understand.

**MS McKENZIE:** No. If we don't ask any questions it means it's really clear and it's not a problem.

**MS JONES:** Do you want me to keep on going?

**MRS OWENS:** You said you were going around in circles but I didn't think you were.

**MS McKENZIE:** No, it's clear.

**MRS OWENS:** I think there was a logical progression through all of that.

**MS JONES:** Okay. I suppose the thing I'm going to say is that I think that if the Purvis decision comes down in the High Court in line with the Federal Court, then there must be an urgent need for legislative reform, and in the written submission I suggested some ways that reform might take place. I'm not committed to any of them. They're working notes, if you like, to start discussion, but it would be terrible - basically Purvis has the power to completely undermine the act and I don't know what the High Court will do. I don't think anyone really knows what the High Court will do at this stage. So that's a really, really important issue.

The next really important issue I've got down here is about disability standards. I wouldn't normally have put that as my next point, except for the fact that the minister - who was it - the attorney-general announced the other day that they were going to go ahead with disability standards in the spring session. Bad luck if anyone wasn't happy with them, "We've spent enough time talking about it." It sounds exactly like my father, "Enough of the discussion. Let's just go and do it. I'm frustrated. I want to move on."

The disability standards have got some inherent problems. Sorry, standards full stop have got some inherent problems, then the education standards I'll come back to in a minute. My first concern, wearing an administrative law hat, is with the disability standards as a piece of subordinate legislation. I spoke with Kym Duggan and various other people about this very early in the standards process and nobody could really satisfy me and they then took up my worry.

Under the normal principles of statutory interpretation, if you have an act like the Disability Discrimination Act and you have any provisions made that are authorised by the act in some way, and you give someone else the power to do those things, and if the thing that you're giving them power to do is rule-making in some way, there are rules about how you have to go about doing it. One is the process of making subordinate legislation and the second thing is what is the effect of subordinate legislation?

In order for disability standards to become law, they should have to comply with the parliamentary process, which means that they're laid before each house of parliament for 14 days and there is the possibility of disallowing them.

**MS McKENZIE:** Presumably, the simple process reason why that hasn't happened is because they mustn't have been declared to be whatever the Commonwealth equivalent of statutory instruments is.

**MS JONES:** If they are statutory instruments then they have to go through that process.

**MS McKENZIE:** But sometimes the legislation that sets out those processes is limited in the way that it relates only to regulations - things called regulations - and you need some extra declaration to bring it under that rubric. If in fact that were the case, I assume you would recommend that it be made clear that standards are subordinate legislation and must comply with the same processes.

**MS JONES:** Yes. My process is it's not only they're subordinate legislation, the Instruments Act, which has really only just started going - about five years ago there was a report, an inquiry conducted into Commonwealth government rule-making and they located 130 different types of things. The legislation required that regulations and disallowable instruments went through a process but the other 128 things - they were called something else - didn't have to. So now there's the Legislative Instruments Act that tells you about the process to go through, but standards don't seem to be fitting into that category and I don't know why not. I can't see any legal reason why you would be able to bypass that process now. So that's one thing. That's the process.

The second point - actually the point in a way that you just made then, Cate, I think is the more important one, and that is standards have to be considered a subordinate legislation, which means they can't exceed the terms of the act. While you could replace the education sections with the education standards, you would still be obliged to read them consistently with the objects of the act and consistent with the earlier parts of the act.

**MS McKENZIE:** Yes. It's a matter I've raised as well at various stages through the submissions.

**MS JONES:** Good, because that's one thing that to me is a very big issue and I just thought I was a voice in the wilderness and it needs to be clarified.

**MS McKENZIE:** They can't supplement the act. They can't improve on the act. They can't add to the act.

**MS JONES:** They can't decrease - - -

**MS McKENZIE:** Equally, they can't diminish the act.

**MS JONES:** They can't diminish the act, and my concern is that certainly the last draft of the disability standards I saw was not satisfactory.

**MS McKENZIE:** Was this transport or education?

**MRS OWENS:** This is extending it - unjustifiable hardship in the Education Act to post-enrolment?

**MS JONES:** Yes, that, but also - - -

**MS McKENZIE:** But there's more, I gather.

**MS JONES:** Yes. In terms of being consistent with the act, the first thing is whether or not the education standards are about empowering people with disabilities or balancing the needs of people with disabilities against educational institutions. I was on a reference group as a community representative. There was me and one other person as community representative of people with disabilities and there were another 15 people from different government departments, and that was meant to be because we were all balancing it together.

The process was unequal but the outcome is unequal, and it's not just about the unjustifiable hardship thing. I've actually got that further down my list, but I actually think that it should also be made clear that defences should not form part of standards. Standards should be about clarifying what it means to provide non-discriminatory education. If you don't like any aspect of what's in the standards or you can't comply with it, then you could apply for an exemption or you could argue unjustifiable hardship, but the big problem is not knowing the defences, the big problem is knowing the rights: what does it mean to be allowed to be included in education?

In one of my less important points down the end here, I've actually said I think that the standard should be inclusive of education; that what we should be talking about is describing inclusive education and that should be the purpose of the standards. If there's a ground for an exception, there's a ground for an exception. There are people for whom there are arguments that inclusive education isn't the right thing.

I know those arguments are put and I know that some parents prefer it. I have never come across a situation, where there is segregated education where it has been good. I've never heard of anyone's experience where it has been good, once they are sat telling you the stories. But I have certainly heard lots of people who say - and it is easier, that's for sure - "You send your child to a special school; the taxi or bus comes and picks them up and you don't have to worry about them for the rest of the day." Gee, it would be nice if inclusion was that easy. I would love inclusion to be that easy.

I had an 11-year-old with an intellectual disability, amongst other things, and she has just read book five of Harry Potter completely on her own and she has got an

intellectual disability. She's my fifth child and she has been included in everything all the way along and goes to the same school my other children went to and they have been fantastic. But I can't tell you how many days of the week I have to fight for things - or I can tell you because you are familiar with the process. I am sure that if I had complied with what the doctors told me about my daughter, which was that I should give her up because she was never going to be able to do anything, including sit, stand, walk - and have other children or, alternatively, "You've already got four, why do you need any more?" And, by the way, she was a failed contraception and I could sue all sorts of people and get some money to do with her disability.

**MRS OWENS:** As from yesterday.

**MS JONES:** As from yesterday.

**MRS OWENS:** Would you?

**MS JONES:** I think this is a very big problem because I think it's the same with the wrongful life cases. This case I don't understand. I do understand it because it was medical negligence but I don't understand the way in which that quantification took place. But had it been a child with a disability, imagine what we would be saying. Yet there are wrongful life cases where people said, "I didn't want to have a child and look at the incredible cost of the disability." I think the only reason people need to bring those cases is because there are not sufficient resources available for them in the first place. They shouldn't have to go begging to the court saying, "I've got a wrongful life here." Their daughter's life or son's life should be able to be valued and resourced in some way.

I just think the law is back to front in all that. But it shows how serious the problems are, that the majority of the sorts of cases - and this was in the context of a negligence claim, and so are all the cases that are called wrongful life. I haven't yet read the judgment because when I printed it my printer didn't have any ink in it, so I printed 130 pages of blank paper, which I discovered afterwards. Anyway, that's a bit beside the point. But the question of valuing people is a very big one.

So with the education standards - okay, let's just go back to unjustifiable hardship. If we are to say that the act is about treating people with dignity and respect, and we are now saying we are going to do it in the education setting, the principle should be that everyone is going to do that. And, of course, what that means is not so straightforward; so yes, it's going to be very important to have rules and guidelines. I've never had an individual education assessment meeting-type thing but it has worked very well with lots of things as we go along. I don't know why I've forgotten the name of those - you know what I'm talking about, the individual plans that are usually specified in guidelines? Certainly the idea of the

American legislation on education has all these things like, "You must have guidelines. You must meet a certain number of times. You must have these sorts of professionals."

I think it's really important that there are processes set down. I think it's also really important that it's made clear that meeting the needs of inclusive education is the responsibility of the state. The individual school is going to be in trouble if they have to fund disability, although they won't tell you this so obviously, but they all get funding to deal with disability; category 12 funding is tagged to the individual child with a disability and schools apply for this funding on the basis of how many children they've got in the school that fit within this category. It's not nearly enough money to pay for resources; it doesn't pay for aides or anything, but it goes into the general school budget, which means that the general school should be providing. But I do think that some of this - - -

**MRS OWENS:** Can I just stop you there?

**MS JONES:** Sure.

**MRS OWENS:** Are you talking just about government schools there, or independent schools?

**MS JONES:** No, I think all schools. I think independent schools also have systems.

**MRS OWENS:** They have systems but we've talked to the Independent Schools Association - - -

**MS McKENZIE:** Numbers of them.

**MRS OWENS:** A number in each state and the national association, and they are saying that the dollars that they get for the children that attend their schools are much less than the kids going to government schools. And they are basically arguing that the dollars should follow the child, regardless of which part of the education system they turn up in.

**MS JONES:** That's true. My understanding is that there are two different sorts of funding. This category 12 funding is the same, whichever school you are at, which is the systemic funding.

**MRS OWENS:** Is category 12 New South Wales?

**MS JONES:** Yes, it's New South Wales. No, it's a Commonwealth funded - - -

**MRS OWENS:** It is the Commonwealth one, yes.

**MS JONES:** Look, I might be wrong because I haven't looked at this for a couple of years.

**MS McKENZIE:** No, I think you are right. My understanding is, certainly from one of the submissions, that a child with a disability gets category 12 into the highest funding irrespective of the categorisation of your school.

**MS JONES:** Yes, and independent of the sort of disability, and there's no - - -

**MS McKENZIE:** And independent of the sorts of disabilities.

**MS JONES:** And the sorts of needs that the child might have, again.

**MS McKENZIE:** Yes, that's right.

**MS JONES:** Because again I have a problem with "sort of disability" because people with physical disabilities do need ramps and don't need ramps. It's not enough to just break it down into those categories but there's different funding, and it's true that the state schools get more money than the private schools do. So if you go to a state school you can apply for federal funding for an aide and, under a formula, money will go to the school. You might not get a full-time one that you want, or whatever. If you go to a private school there is no ability to apply for that same sort of funding. So if you get an aide, lots of the time it's parents paying with their own dollars.

A lot of the time it just doesn't happen, or you have some special ed teacher who isn't really doing the job of inclusion, they are doing the job of exclusion by taking the children out of the ordinary classroom to be taught somewhere else. But the bottom line is that none of it is funded adequately. I think the state schools have got every right to complain that they don't have the resources. They certainly have worse general funding. So the staffing levels, the equipment, and all of those things - and to an extent disability does cost money. If you need to have extra computers because you've got children with disabilities - if you are a school where everyone has got a computer it doesn't matter; it's not extra for you. But if you are a school where not everybody has access to a computer, it is extra.

Really, and this goes back to the thing you were talking to Jack about, the cost of disability is very difficult. But I think what's important is that the standards should be used to work out how to empower people, and the processes of HREOC and the court should be to determine if there are grounds for an exemption or a

defence to make whatever you want to do lawful. That should be the whole way the act is written and processed, that this should be about how we empower people in employment, not about how we have excuses to say, "Well, you don't really meet the inherent requirements of the job."

I have to tell you that when I became ill I went to a meeting and the university waved the Disability Discrimination Act at me and said, "Isn't this wonderful?" And I said, "What you are doing doesn't comply with the Disability Discrimination Act." They say, "You can't meet the inherent requirements of the job." And I said, "That's total and utter nonsense." And they said, "We don't believe you can and that's all we are going to do, so therefore you don't have a disability claim," which they are completely and utterly wrong about. They used the DDA as a sword to get rid of me, and they won't hear the end of it. It doesn't matter; I will deal with it.

**MRS OWENS:** I was going to ask, are you going to put in a complaint?

**MS JONES:** I hope not, because I hope we will negotiate something without having to go through the process, and I think that's another problem. Going to law should always be everyone's last resort.

**MRS OWENS:** Yes.

**MS JONES:** And that's why the individual shouldn't have to put a complaint about education discrimination once you've got the basic standards in place. The people who go to court to worry about it should be those who don't want to be non-discriminatory. Those who want to discriminate should have to be the ones who go to court, because it's too expensive for individuals. My next point here is about the complaints process.

**MS McKENZIE:** Enforcement of the standards shouldn't be reliant on the complaints process at all.

**MS JONES:** No, you should never have to have an - - -

**MS McKENZIE:** Yes.

**MS JONES:** But at the end of the day, if the standards work properly, no person with a disability should ever have to go to complain about education, or even whether they can go to HREOC or the courts. No-one should have a complaint that they have been discriminated against in the process, because the standards should sort out how this is all going to - what you can get as the person and how the balance lies. At the end of the day, though, the institution might still say, "We don't want to provide it, even though it says it in the standards." And I was thinking about this

with respect to new buildings, and thinking there should be no exemptions with respect to new buildings, and I know other people have said this too under the premises section; and I am jumping here.

But then I was thinking, the problem is if you don't have an exemption process there's going to be the odd case where there really is a good ground for there to be something that's not completely compliant with the disability standards. I'd have no problem with an exemption process if the emphasis was that you are expected to do this; the expectation is that you will comply and if there is some reason why you can't, then come and talk to us. And I think that should be the same with education. There is an expectation that you should provide non-discriminatory education and if we can't deal with it for whatever reason, we go and talk to the people and ask if we can be exempt. It just depends on the emphasis.

Just whilst talking about premises, for a minute, I discovered recently something that I think goes to my public and private thing in this check list. It appears that if you go to a local council and put in a building application to renovate your house in order to meet the disability needs of someone living in the house, the local council is allowed to refuse to allow you to do any of these things; like have wider doorways than the normal ones and have ramps in your house and whatever. And they say that they are not discriminatory because they accepted your DA across the counter. Now, it seems very clear to me that while the building standards and all of that stuff was focusing on public buildings, a local council is discriminating if they won't allow you to take positive steps to accommodate your own disability in your own house.

**MRS OWENS:** Would that ever happen?

**MS JONES:** I actually know someone who has been going through the Environment Resources and Development Court and their case has been thrown out three times now. Apparently this woman is a lawyer and she told me they have other cases where the same thing has happened.

**MS McKENZIE:** So they won't let you modify your house?

**MS JONES:** They won't allow her to modify her house.

**MS McKENZIE:** Why?

**MS JONES:** Because what they want to do is non-standard. They want to have the doorways wider. Their daughter uses an electric wheelchair, can walk a little bit but the steps that they had were dangerous, or the size of the steps - whether they were too big or too small - were dangerous. They wanted to put a lift in so this child could

access both parts of the house. They would have paid for it all. The council said, "No, it doesn't fit with the normal regulations." And so what is happening - and it seems there was another case of someone who wanted to put a ramp at the front of their house, and in that case I believe it was Manly Council who said, "No, you can't, because we don't allow ramps in the street." They wanted to take their ramp out into the street so they could actually get from the car into the house.

**MRS OWENS:** That's really hard to understand, because the Building Code has got very broad requirements.

**MS McKENZIE:** Yes, and then it says, "If you do A, B, C, D" - and they are very specific things - "you are deemed to comply with those very broad requirements." Like you were supposed to have safe access around the house. And there are 15 million ways you could dream up to have save access around the house. It's as if the council didn't realise that there's this second alternative that can be used.

**MS JONES:** All I can tell you is that I now know of about 10 cases of people in New South Wales where this has been an issue. And I think it's an issue because it is not made clear. In that case I think they have attacked it in the wrong way. I think it's discrimination by the local council, not to do with the development. Like, they are discriminating in the way they are making their decisions. But they have actually - one of the people, at least, spoke to HREOC and was told that they couldn't bring an action.

**MRS OWENS:** And what was the basis for that?

**MS JONES:** They took the building application and they considered their duty was to consider building applications and not to be non-discriminatory in the process. It sounds very weird.

**MS McKENZIE:** I don't think that fits with the case - - -

**MS JONES:** Actually there are no reported cases that deal with this particular issue. But if you are talking about a Building Code, you have to comply with the Building Code when you are making a new building. When you are doing a renovation, and it's to do with a public building, again the Building Code specifies things. It's clearly not going to be the case that every house has to have ramps and stairs to meet the people who can use the ramps and can't use the stairs - or can't use the ramps, and to meet their needs. Obviously there can't be a positive duty on individuals to make their house accessible if there's no reason why they need it to be accessible, although having friends over is much more difficult if you don't. Jack would probably never come to our place and - you know, we are able to put a ramp out but when we were doing the house up it didn't occur to us to think about that

issue because at that stage no-one in my household used a wheelchair.

The other thing that is important about this thing is that it's a different way of thinking about the way the act operates, because in this case we have someone who wants to do something in order to make their lives work; it's not really to do with the act. But in the non-discriminatory process apparently there are still local government regulations that specify standard door widths and things like that. I don't know.

**MS McKENZIE:** Yes, there are.

**MS JONES:** I haven't looked into the detail of it. I'm just telling you what I've been told by a number of people.

**MS McKENZIE:** It's a confusion I think. What those regulations do is pick up the Building Code of Australia which, like I say, has very broad performance measures, but then says you're deemed to comply with those very broad performance measures if you do very specific things like have doors X width. But what the council doesn't seem to understand is you can comply with those very general performance measures in another way.

**MS JONES:** Well, that's right, but the things is that the Building Code looks like it applies to builders.

**MS McKENZIE:** Yes.

**MS JONES:** I think this is what I'm saying. Clearly the Building Code, as there are decisions made under it, must apply to councils as well.

**MS McKENZIE:** Yes.

**MS JONES:** But I just think the thing is people think in categories, you see. Building Code is this, the local council is that - hence my check list. I know lots of people have talked to you about the complaints process being too costly and user unfriendly. Another thing I want to say following on my check list is that my understanding is that the DDA has done as much really as you could expect with a piece of legislation of its nature in the short period of time it's been operational, with respect to people with physical disabilities and sensory disabilities. Okay, most of the cases and things - no, that's actually not true, but most of the successful cases have been in that area. I started doing a survey but it's so out of date I can't tell you whether that's true any more.

But I know for sure that people with intellectual disabilities basically feel completely disenfranchised by the process and by the act. Putting ramps in and

putting information in big print might help in some cases but it might not; but putting Braille on the ATMs, all of these things which are very useful whether or not you've got the disability concerned, don't meet the needs of the person with the intellectual disability who wants to use the voting system, who wants to use the bank, and discrimination for a person with an intellectual disability is as extreme as it is for other groups of people with disabilities.

The sort of issues of physical abuse, the fact that - I know that the research shows that somewhere between 70 and 98 per cent of young women with intellectual disabilities have been raped by the time they're 18. I've said to my children that Alicia is not going to be one of them, she's going to be in that - but it's a really big issue as a parent knowing that the chances, statistical chances, of my child being raped are unbelievably high. The fact that there are still sterilisations that go on, that doctors are sterilising them - doctors should be being sued for acting unlawfully. The law is very clear. You have to get a court order before you're allowed to do it; but they do it anyway. Of course, if anyone told the doctors off they would say, "We have to raise our insurance again."

But I do think the big problem here is this problem of responsibility. Who's going to make sure that people comply? We can't get the doctors to comply but we can't do anything about it if they don't. There's no access to making a complaint about it. It's a matter for investigation of a system. That's why I would say one of the things that I think is incredibly important, which is under my HREOC list or to do with HREOC - it's actually point 11 on this list; that we need an independent monitoring body, and that monitoring body needs to have the power to be proactive, to investigate things like the sorts of things that I'm talking about that are exclusions but not necessarily so clearly discriminatory.

They need to be able to monitor to make sure that the standards are working. In education they should have the power to drop into a school unplanned, unannounced and go and see whether things are really working. And they should have the power to issue on-the-spot fines or something. I don't know, I haven't really thought it all through. But they've got to have teeth attached to it. It's absolutely useless if you have a body that monitors it and you get another report and everything stays the same. The body has to have teeth of some sort.

Now, I am very concerned about the funding of HREOC. HREOC can't do its job. The disability unit consists of three full-time people. You could not possibly load them up with anything like - on top of what they already do; and in fact they can't do what they do properly because they haven't got enough staff. However, it would be efficient - if we're talking about competition and efficiency - to locate an independent body within the disability section of HREOC, because that way they would share the resources: the library, the expertise. But the danger of that would

be that they could get caught up in HREOC's general funding and that would be the end of the day.

So I just think that I can't emphasise how important this independent body should be, and HREOC should be able to initiate complaints. There's a problem with HREOC initiating complaints, which is the problem of them being both a party and - in terms of separation of powers doctrine, so setting up an independent body outside HREOC, though it may be physically located very close so they can do a bit of that sharing resources; setting up a disability ombudsman, for example, in addition to our rights-based legislation, not instead of, with some sort of proactive power could be a solution here. But again it has to be properly resourced and have teeth.

There's one other thing that I actually think I have in my secondary list. Sorry, there's one other thing in my important list I haven't mentioned, which is I think it would be very useful if the act were to include - it's point 7 on page 2, Helen; if the act included a duty to make accommodations.

**MS McKENZIE:** Many people have raised this also.

**MS JONES:** I'm glad, because I think it's very important that - again it goes to meeting the objects of the act. If the object of the act is to eliminate discrimination, then one of the things people have to know they've got to do is positively act. It requires you to take positive steps. Once you know you've got a duty to make accommodations, if you can't for some reason then you go and apply for an exemption or you know you have a defence for a case. But the presumption should be if you are an employer, if you're a school or if you're a cinema, it shouldn't matter where, that you have a duty to accommodate the needs of your community with disabilities. That could just be put within the context of employment but I would prefer to see it as, you know - - -

**MS McKENZIE:** Relating to all the areas?

**MS JONES:** I'd like to see it as part of a general proposition. I actually think the act should - if I was starting from scratch and if I wouldn't say that this I think would be an extraordinarily dangerous thing to say, I would redraft it. But I think that would be a disaster because we've got something that's good and you couldn't be sure that what you're going to get is going to be better, which is why I've said the small points in my submission are for discussion but I'm certainly not really advocating radical revision of the act, which is why that was my first point.

**MS McKENZIE:** But the duty of reasonable adjustment you think could be included but should be a general application?

**MS JONES:** Yes. And again I would talk making accommodations, maybe including a definition in the definition section of adjustments or whatever. One of the things we know for sure when we're talking about the cost of disability is a large number of accommodations are made by people without thinking about it. If we were to go to put an economic cost to that, we would actually find that the cost of making adjustments once you'd worked out a mean was actually very low.

Some organisations might have very high costs, but given the number of times people just do things, you know - someone with a visual impairment has told me in her job that they had normally had a meeting, someone talked through all the things that had to be done that day at the beginning of the day and they changed the system to put it in writing. She couldn't read it. She didn't have to go and make a complaint. She spoke to the boss and the boss said, "Fine, I'll just read it out to you when you get there."

So, I mean, there are ways of making these little adjustments without - and the thing is, the only thing people talk about are the big deals. I think that's a very important aspect of looking at the whole question of the cost is if the cost is spread throughout society, of whatever it is, the cost is very low. The cost is only very high when some people have to do it and nobody else has to do it.

Just on that point about the cost, one of the things that people don't think about often, but feminist work has gone on with respect to women generally, is women's housework has never been given a proper equation economically. What is the economic value of women's work, the unpaid work? Then you take that into the volunteer sector and you take it now into the case of carers. I mean, the government gives you some very small sum of money, because you're a carer, that will allow you to buy a coffee once a week, if you're lucky, on your own.

**MRS OWENS:** You're talking about the carer's allowance?

**MS JONES:** The carer's allowance - but I actually think that there should be some point of compensation somewhere. These people who are carers, who aren't being paid, are providing an economic service to the society. People who are volunteers working for organisations are also contributing to the economy. So when we're doing the equation we need to go through and think about all these different categories of people. The cost of having to have an interpreter because the grandmother wasn't going to look after the child and the child didn't speak English - it wouldn't be just the ordinary cost of getting a child care person, it would be a child care person with those qualifications. So I just think when we're talking money, we have to make sure that we're very inclusive of these sorts of factors. On page 3, being aware of the time and you're probably all fading away - - -

**MRS OWENS:** We're not fading away. I could live on my resources for a month.

**MS JONES:** You'd be very skinny by the end of it.

**MRS OWENS:** No.

**MS McKENZIE:** That might be a dangerous statement.

**MS JONES:** They might write, "You can have pay, but not for food."

**MS McKENZIE:** That's right.

**MS JONES:** Okay, on the competition points I think we need to realise that this issue about spreading the cost - if all businesses make the same sorts of adjustments, then there's no competitive loss and in fact I think there's quite a lot of evidence that people have found accommodating disability is very good for business. The reason I say that - again, the article from Melbourne University Law Review discussed this a little bit more, I think. If you look at McDonalds' web site, if you go to some of these chains, McDonalds have a fantastic action plan.

It's obviously considered good for business that they're saying to people with disabilities, "Well, you can come to us. You can't go to Hungry Jacks because they don't have an action plan," or, "They're not being accommodating in the same way as we are." While only some places do it, they get the advantage of having all the clientele of people with disabilities who now discover they can go out somewhere to eat. They have the advantage of all the other people who are the unintended beneficiaries.

I made my first disability complaint to the local post office without going through HREOC when my 10-year-old walked my baby down to the post office with a parcel but because she was in a pusher she couldn't get her into the post office, so didn't post the parcel after all. You know, it was an hour's round walk. As it happened, the child was the one with the disability who was in the pusher. In fact, she was still a baby who would be in the pusher anyway. But the point was, it was not accessible. How can you have a post office that's not accessible?

But let me tell you I had five phone calls after making that complaint just to the local post office. So people are prepared to try and do something about it if they're alert to it. I actually think that's one of the other responsibilities that people have got: to talk about it. It's hard to talk about your needs. It's hard to ask for help. But I actually think that very often people won't know that there are different needs if they're not told about it.

**MRS OWENS:** But some people are in a better position to talk about it and make their requirements known - I'd suggest you're one of them for obvious reasons - and other people find it extremely difficult.

**MS JONES:** Yes. That's why we can't ever - what we have to say is that those people who are able to do things have to do them and those people who aren't should be equally respected whether or not they can or can't do it.

**MRS OWENS:** I think the whole mood of what you're saying, the whole theme, is we shouldn't just be relying on people having to bring it to people's attention. You need to build it in - I hate to use this word, but embed it.

**MS JONES:** Yes. Well, you have to embed it in the consciousness as well as in the legislation.

**MRS OWENS:** Yes.

**MS JONES:** I'm not sure about this point, but you might be able to tell me. At the moment I don't think an NGO can bring an action, bring a complaint on behalf of people. I know that you can complain if you're an associate of the person but that's because you've been discriminated against because of your association. There are those series of other people and that's again another very important part of the act. You know, we've got some really good things in our act and that's another one of them.

**MS McKENZIE:** The answer is, we'll have to check very carefully because there is disagreement in the submissions about what the act permits. Some say it permits it; some say it doesn't.

**MS JONES:** Well, I don't think that it does permit it.

**MS McKENZIE:** But if it doesn't permit it, you think it should?

**MS JONES:** And I also think under the general rules of standing you might be able to make a case anyway now; but I think NGOs should be able to bring action but the important part is I don't think it should have to be a representative action. I don't think it should have to be on behalf of a person with a disability. So someone can bring the action. An NGO can bring an action for me if I've got a complaint and they want to act on my behalf. The NGO can definitely initiate that because they can be my representative.

I think that's quite clear. What I'm talking about is an NGO that knows about the state of discrimination of all their members - you know, the people that are

working in the intellectual disability field who know that there's a particular sort of problem. There is no particular individual on whose behalf they should bring it because - and this again is the problem with anti-discrimination legislation if you leave it as a complaints process - a lot of the things are systemic or institutional and you can't find the actual individual or whatever harm it is to a particular individual is negligible so they wouldn't be taken seriously. It's just when it affects large groups of people I think it should be that NGOs should be able to initiate actions on their own behalf, as they are under the Race Discrimination Act, by the way - under the racial hatred provisions for sure and I think across the Race Discrimination Act they're allowed to. I don't think it's in the DDA but I stand to be corrected.

**MRS OWENS:** As Cate says, we'll have to check that one.

**MS McKENZIE:** But certainly I understand what it is you think should be done if it's not there already.

**MS JONES:** One of the points that I've got - it's actually my last point on page 4, Helen, that I'm referring to - is about action plans. Now, the idea of having action plans in the legislation was a brilliant idea. It's, as I said, the idea that people in the community take responsibility for dealing with and eliminating discrimination against people with disabilities, that it puts the issue of disability on people's agenda and it requires them to do some thought about it but there are really big problems with the way the whole process to do with action plans works.

The first one is that you can register your action plan but nobody has checked whether it's consistent with the act or not, so I actually think that all action plans should be certified as being consistent with legislation or not. Now, if HREOC is going to do that, they need an extra staff member to do just that job of looking after action plans because in order to see where the action plan - now, the idea of an action plan is that you've got to plan it over a period of years; you will change your business from being inaccessible to being accessible and the concept of action plans being voluntary is that the local shop can have one, your sporting club can have one and a federal government department can have one and, while they were mandatory in some environments, the fact that they are not mandatory in a number of big areas I think is a problem too.

I think every individual educational institution, not every system, should have action plans to do with disability discrimination. I think that some schools will be in a different state in terms of their ability to include children, and so the action plan for one school will differ from the action plan of another school, even within the Department of Education, but I do think every school should be expected to have an action plan - I think all government instrumentalities, whether or not they're government departments.

You know, one of the ways is in deregulating things and making various bodies not government bodies but quangos and other such independent institutional bodies. They're able to avoid a whole lot of the legal regulations. They don't have to comply with the Freedom of Information Act. They don't have to comply with this, they don't have to comply with that. Government departments had to put in action plans but state instrumentalities didn't have to in terms of what was mandatory. I think it would be very good to think of mandatory action plans as something that any organisation of any sort that deals with large number of clients, who may or may not be people with disabilities and probably not - they might have no clients with disabilities because nobody can get there or know about it - so I wouldn't want it to be based on having people with disabilities. I would want it to do with the size of the organisation.

So if an organisation employs more than 20 people, say, that again is just an idea, it would be very good but it's no use having an action plan unless the action plan complies with the act and you should never be able to get an exemption for anything unless you have an action plan associated with it which is consistent with the act, as in "we can't act in a non-discriminatory way now but we hope to be able to over the next five years" and, of course, if the action plan has been registered, then it should operate properly as a defence to a complaint. At the moment there's a problem that a lot of potential respondents in cases have. They've got an action plan and we know the action plan could be taken into account but people don't know whether their action plan is valid. You can't even get that information. HREOC won't tell you, "Yes, it looks pretty good," because they can't do that. They could get themselves into a mess if they started looking at some people's plans or whatever.

**MS McKENZIE:** Not others, yes.

**MS JONES:** So there should be a registration process. The action plan - you know, at the opening stages of the act I thought it was the action plans that made our act what it was. I still think we've got lots of potential but in fact they haven't lived anywhere near up to their potential. On the other hand, the inquiries and some of the self-regulation that's been developed is something that wasn't expected and it has turned out to be very valuable without any doubt.

I think the DDA has to get credit for a lot of things even though those things aren't specifically part of the act. On the one hand I think you have to say the DDA does things; on the other hand you've got to be very realistic that law can do very little on its own. So how you assess the actual role of the law in the improvement of things is again another question - even if you can work out there's improvement over time, to what extent that could really be attributable to a piece of legislation - but people have organised themselves around issues to do with the DDA and, without

those issues around to discuss, they may have never come together on a lot of those things.

So there is really a value in it but, again, maybe someone has to look at the self-regulatory scheme and see if it's consistent with the legislation because I could imagine that people would think we've got something wonderful going on and it might work wonderfully for one group of people with disabilities and completely disempower another group. So I really think we need an institution of the state and I actually really think that this business of registration of action plans should be the disability ombudsman's responsibility as well.

You know, the whole thing about monitoring the operation of the act should be away from HREOC. HREOC should still do everything it does but the monitoring processes should go to the disability ombudsman, which is either part of HREOC or - I don't know that that's the right term and certainly in countries where they have disability ombudsmen they've been doing inquiries into the problems of disability ombudsmen. I was recently involved in a project with the Swedish government. The Swedish ombudsman commissioned a report on the DDA that Leanne and I wrote and it was, of course, very positive the whole way through. We didn't have any of the critical things we might say to you in it because, as a model, we think it's very good and what Sweden is talking about doing is complementing their disability ombudsman with a human rights piece of legislation.

So the fact that I'm talking about saying, well, our DDA is actually a nice piece of legislation and it can work for human rights and we have an ombudsman-type office or ombudsperson - if you think the "man" bit is sexist, or whatever, commissioner. I actually think "ombudsman" carries with it the implication of investigative power and respect and commissions. There are so many different sorts of commissions that I don't think that immediately says anything to anybody, so a disability commission may not be what we want but we definitely need an independent body to monitor what goes on and perhaps longitudinal studies could be commenced by this body to establish some aspects of the cost of disability.

**MS McKENZIE:** You think a disability action plan should be mandatory for government agencies. Is this fair?

**MS JONES:** Yes - - -

**MS McKENZIE:** .... and to oblige organisations you said I think - - -

**MS JONES:** Well, if you look at the affirmative actual legislation and look at who's obliged to follow those guidelines - - -

**MS McKENZIE:** So something similar.

**MS JONES:** Yes, something similar. I mean, I don't think it's fair to require a small business - you know, this question about small business and extra paperwork - I don't think it's reasonable to burden a small business with that extra effort but as soon as you've an organisation that's big enough to talk as an organisation about its mission and what it's trying to do and its place, then that organisation should be required to take this into account.

**MS McKENZIE:** You could have a small organisation that's contracted to government where it could be built into the contract if that's something that's required. So there might be exceptions there.

**MS JONES:** Yes, I actually think that all government contracts should require compliance with the DDA and the SDA and the RDA. I think all tender documents should state that this is one of the things that is being looked for. I think that there should be funding that employers could apply to a fund for the cost of expensive accommodations, that there should be government funding and what they buy should be tax deductible, but the funding should be available in some way which would be a way of dealing with the cost of very large items. But I think the taxpayers' money in supporting disability discrimination, that would be a way of sharing the burden if you had some sort of fund.

Again, if you had some sort of fund or a body that was designed to help in accommodations, with expertise to tell you what sort of accommodations, what sort of equipment is available, whether it was up to date - you know, like again an information place would be very useful. But I think that there should be - you know, we should be looking at questions like how the taxation system should be looked at; without any question the private cost of having a person with a disability in the household or in the family, however you define that family, is significant. You know, Jack was just saying about the car and the fact that he hadn't even thought that you needed the wheelchair lift. There are just so many extra costs but allocation of funds should be on the basis of need, not on the basis of classification.

I don't think someone having a physical disability should be entitled automatically to A, B and C. I think a person with a physical disability who can't walk should have access to things that people who can't walk have and it shouldn't matter whether the reason they can't walk is because of a chronic illness or a physical disability or because they're an amputee. You know, the categories should have to be fluid. I have another child who has got a chronic illness so I've got a lot of expertise in this and my 11-year-old who has got the intellectual disability can get access to all sorts of respite and all sorts of things like that that we haven't used. We haven't found it useful but my daughter who is now 19 did not go to school most of her

school career. While I could get funding for Alicia for someone to come and do her work with her after school, et cetera, nobody would ever give us any support with respect to the chronic illness.

So from my personal experience I shouldn't have been able to get things for Alicia that I didn't need but I could have got them, but there should have been a way that somebody could help me, even if it was with knowledge of what to do - you know, we've just spent a fortune on a wheelchair which we've had from the chemist for the last - I don't know how long - because we gave our wheelchair back because we thought we'd stopped needing it and we're now on a waiting list that's been nine months or something. We've been on a waiting list to get it from the local pool of wheelchairs.

We wouldn't be the only people who are caught in that situation. I'm beginning to think we should have just bought one, though, but we didn't want to buy one. We thought it was temporary, and so I think there should be ways. There are schemes but the schemes are so limited and so difficult and the biggest problem I think with all of these things is knowledge, you know. I found out about respite for my little one when I went to Tumberton to get an assessment and at that stage I was pulling my hair out and I had nowhere to go with her or anything.

**MS McKENZIE:** And that was by accident?

**MS JONES:** What I'm saying is everything I know about, I know about either by accident or because I know somebody whose child has had a - you know, personally - as in just in my circle of friends or extended friends. I'm a highly educated literate speaker of English and I can't get the system to work. I can never understand anything ever that comes from the Department of Social Services.

**MS McKENZIE:** I think everyone else would agree with you on this, unfortunately.

**MS JONES:** And every single time I get one, it sits in a pile until I've got time to make a phone call. So the whole thing about information - government departments, particularly government departments dealing with people with disabilities, should be obliged to make sure that they communicate, not in plain English because I think that's a very abused term, but communicate in an accessible way.

The information has got to be something that can be understood by the people using it, otherwise they win out; they win out all the time because people don't make the claims because it's too hard. It's the same - people don't use the law, it's too hard. A lot of the issues though relate to one category of disability and not to others. One of the big issues with the social model of disability was it was developed by boys in

wheelchairs who had all had accidents on sporting fields, who didn't have other physical problems associated with the loss of use of their legs which is what virtually everybody else has. It seems that 4 per cent of disabilities are caused by genetic factors, so why are we spending valuable research dollars on trying to deal with genetic issues when that only deals with 4 per cent?

In the world context I say, "Well, why don't you just have clean water? It's a much better use of money, making sure everyone has clean water." I'd say in Australia we shouldn't have to make that but there are still indigenous communities that don't have clean water; think of the disabilities that are created by that. Think of the disabilities that are created in the Northern Territory by the number of kids who don't have access to antibiotics so have hearing loss through a number of their years of schooling; they miss out on schooling. How on earth can we look at the indigenous population and say we're moving towards reconciliation if we're not being sure that preventable disabilities are prevented? Nutrition for pregnant women is another cause of disabilities in the children, so all of those things too need to be taken into account. So I think that covers what I needed to say in terms of today, I hope, but I am very happy to talk with you further about any of this.

**MRS OWENS:** I've been looking at your yellow pages here and I think we've covered quite a lot and the few that we haven't, I think, are self-evident. There's a huge amount of material in your draft submission which has given us a lot of food for thought. Do you want to ask her anything else?

**MS McKENZIE:** No, I think we've covered the most important things. I've asked you questions in the running which has definitely been the easiest way to do it. Yes, it's a tremendous submission and the discussion is really interesting.

**MS JONES:** Thank you very much and I will finish the submission for you, but please don't put it on the web site till it's finished.

**MRS OWENS:** No, we won't. I don't think it's there. No, it's not - just to check.

**MS JONES:** Good. It's really a bit messy.

**MRS OWENS:** Thank you very much indeed. We'll resume at 1.30.

(Luncheon adjournment)

**MRS OWENS:** The next participant is the Australian Federation of AIDS Organisations and the National Association of People living with HIV-AIDS. Good afternoon and, for the transcript, could you please give your name and your position with each or both organisations.

**MR LAKE:** My name is Rob Lake and I am the convener of the care and support portfolio for NAPWA, which is the National Association of People Living with HIV and AIDS. This is a joint submission from NAPWA and AFAO. AFAO is the peak organisation of HIV NGO service providers in Australia and NAPWA is, I suppose, the peak organisation of the organisations of people living with HIV and AIDS.

**MRS OWENS:** Thank you, and thanks for coming this afternoon, Rob. You do want to, as you said before, introduce your submission so maybe I will hand over and you can do so.

**MR LAKE:** Okay, thank you. We really appreciate the opportunity to be involved in the inquiry. We have a very strong interest in the DDA and in the retention and, I'd say, the strengthening of the DDA, and that's why we made this submission and we'll be following up the submission as the inquiry proceeds. I suppose the key issue for us is that, whilst the epidemic has changed in Australia and, I suppose, has a different profile to what it used to have, HIV and AIDS continue to have significant impacts on the community and discrimination has a significant impact on the lives of people with HIV and AIDS.

The most recent research that was done - which is called HIV Futures 3, which was published in 2001 reported that about 18 to 20 per cent of people had experienced some form of discrimination in the last 12 months, and so it's an ongoing issue for us. Various people, individually, and I think there has been some sort of representative use of the DDA ever since it was introduced - and I suppose we've had differing success in that, but at least have been keen to use the legislation as it occurs. Indeed, I suppose the other part we are also keen on is the other processes that the DDA embodies, such as the standards and the educative role.

Our main involvement in the standards development was around employment and we had some fairly positive things to say about the development of an employment standard at the time - we weren't so keen on that particular draft - but discrimination in employment continues to be a critical issue, particularly as more people now are recovering their health to a point where they seek to re-enter the workforce and they can only do that with some form of accommodation or flexible work practice, which requires disclosure and which then leads to discrimination.

We really support the DDA and, I suppose, in terms of some of the issues the commission has asked about, the definition is a great piece of work in terms of how it

relates to people with HIV and AIDS and the related discrimination that comes from being perceived to have it and those sorts of things. It is a really well thought through area for us and I think people have used it in those terms as well, and as we've noted, other people - like associates - who have been discriminated against for similar reasons have also used it. Those are my opening remarks.

**MRS OWENS:** Thank you. Your submission has quite a number of recommendations dotted throughout as well, which is very useful for us. In terms of where we have got to with HIV-AIDS, do you think that the existence of the act has had an impact in terms of people's attitudes towards people with HIV-AIDS or have you not really noticed a great deal of difference over the last decade?

**MR LAKE:** That would be hard to say. I would probably draw your attention to David Buchanan's submission, as well, because David is a long-time AIDS activist and been involved with the setting up of the AIDS Council in New South Wales. I think what he tried to do was to draw a bit of a historical link through some of the legislative stuff that had been done and I think it would be hard to say - there is a sense of almost an assertiveness of mind that there is some backing to it, and that might be around some of the advocacy organisations. I think probably maybe organisation like ACTUP might have felt some sort of rights backing.

I mean, we make the point in our submission that one of the things that is interesting about HIV and AIDS and the Australian response - which is known as the strategies - I think they're up to the fourth national strategy - is that they do work on the basis of, there are human rights issues involved as well, and that's been really significant because, for a long time, the people who were principally at risk were people who were engaging in criminalised behaviour; whether that was gay men or whether that was sex workers or injecting drug users - and being able to actually do health promotion work, do prevention work and things like that in that environment is really difficult. I think the strategy recognised that and the DDA and the New South Wales legislation were pretty fundamental in backing that up.

**MRS OWENS:** Yes.

**MR LAKE:** So even though homosexuality has only recently been decriminalised there was an anti-discrimination sort of thing that preceded that to sort of like cover-all, as I say.

**MS McKENZIE:** But it's really hard to disentangle all the factors that might have been leading to change.

**MR LAKE:** Absolutely, yes.

**MRS OWENS:** You mentioned earlier that there had been some complaints with mixed results. Have you got any examples for us? We're interested in the processes and how people have found using the act and how they have found making complaints. What the barriers are to making complaints, and so on.

**MR LAKE:** Yes. I think it's a credit, the fact that people actually have used the act because I think it's a big task for one person to take on and, in these cases, to take on the Commonwealth Employment Services; to take on the insurance company; to take on the defence forces. These are pretty major undertakings, and though really, I suppose, the Centrelink one would have been the most obvious success in that, I think the educational value of taking those on - both within the sector and within the health group - is I think also important to recognise because one of the things that the HIV Futures report says is that a significant amount of the discrimination actually occurs within the health sector on an ongoing basis.

This often is as a result of disclosure and then the consequences of disclosure, so the educative role of people taking action, I think, really can't be underestimated. I actually was trying to find out from HREOC recently about what sort of cases are under way at the moment and they didn't have any HIV cases under way at the moment. I'm not sure what's going on in the ADB in New South Wales. The last bit of research that was done said that the numbers of reports to HREOC had declined and the numbers of complaints to the ADB were fairly steady, and that was post the changes to the HREOC act, and so there was a concern about those changes to the act making it more difficult to access the system, because the ones we have quoted are actually quite old cases. They all would have happened in the 90s. It has been a while since there have been any significant cases taken.

**MS McKENZIE:** There may be a number of factors that lead to that; one of them might be the changes to the act and the others might be for some reason - some lack of willingness to make complaints.

**MR LAKE:** Yes, probably for a full range of reasons people may be reticent about making complaints, as well.

**MRS OWENS:** Some talk about the sort of stigma that may be attached later or potential victimisation.

**MR LAKE:** Yes, because that's the thing. I mean, there aren't really - there are protections around for asthma and things. How those protections work has never really been clearly stated or, you know, put into action. The concern we had, particularly where disclosure elicits discrimination and things, is that the consequences of those are most pronounced in smaller communities, whether those are geographical small communities or a small group of people and things like that.

That's really where it is most hard. I was told about a case just recently of a service provider who basically felt that it was their duty to inform everybody in the organisation of a client's status because they felt it was their right. It was a small town and it went through the whole community and that person hasn't followed up any complaint because they are scared to actually make any waves at all.

**MRS OWENS:** It might make it really difficult for them to live in that community if they made a complaint.

**MR LAKE:** Yes, at least to receive the service allowances to maintain in the community, as well, and I think that is where the idea of other people initiating - ideally, HREOC initiating - things on people's behalf, because over the last - it would be over the last couple of years we have been trying to make some sort of progress around the issue of insurance discrimination - particularly say in terms of an inquiry through HREOC - and often it comes back to finding the person who wants to put their name to the complaint and sort of who is the link point back, and that's a big ask for people.

**MRS OWENS:** I suppose for HREOC to initiate a complaint - or even your organisation, or one of these organisations - you need to be able to bring together a body of information about what has gone wrong, if anything, with insurance, and what the Breast Cancer network have been doing recently is, they have been surveying their members and asking questions about, "Have you had problems accessing different types of insurance?" - including income protection insurance, travel insurance and so on - and they're putting that material together and, hopefully, we'll get to see that at some stage when it's completed, but that sort of material, depending on the results that come out of the survey, would be very valuable material to try and put something forward that would lead to more systemic outcomes. As you say it is very difficult for the individual to run the case often because - well, there are various reasons which we've been hearing about and you probably could also highlight for us, just in terms of potential cost. We've talked about possible harassment, complexity - - -

**MR LAKE:** Yes, and just I suppose the divisibility and disclosure that people would need to - if they want to take it on to the Federal Court and things like that and, I suppose, the personal resources that people need to be able to follow through on those. I mean there is one specialist HIV-AIDS legal service in Australia, and that's in Sydney and they have a very - I think they have one solicitor - they're a very small service as well. Like a lot of those types of services, they really have to try and focus on systemic work rather than individual work. That's a really interesting idea, about the breast cancer. Because there are such a range of issues that the various types of insurance cover, particularly around health insurance and where Medicare is going, that's increasingly significant. I think we're interested - the Mental Health

Council - - -

**MS McKENZIE:** The memorandum of understanding?

**MR LAKE:** Yes. That's a really interesting model, to look at some sort of agreement with the insurance industry on the basis of that, maybe through particular types of insurance that are key. At the moment, I suppose - going back to work, that's where it's sort of coming up for people.

**MRS OWENS:** So what sort of insurance areas would be key - income protection?

**MR LAKE:** Income protection, disability protection. Health insurance is a really great area. It's really unclear - the health insurance industry, they don't actually specifically address HIV and things like that, in them and their product.

**MS McKENZIE:** And they can't discriminate against people.

**MR LAKE:** They can't discriminate. I've just taken it out, and so there's like a 12-month waiting period, but there's no acknowledgment of - I don't know, there's no actual acknowledgment that I've disclosed to them and said, "I've got HIV. This is what I want," so it's really unclear what constraints they will bring in further down the track. A lot of people I've spoken to just don't even bother going for private health insurance because they just think they won't get it because they're positive. So it's one of those - - -

**MRS OWENS:** There's misinformation there because they can't deny access to insurance products based on your health state. All they can do is put you on - there are pre-existing ailment clauses, but that applies to everybody with pre-existing ailments.

**MR LAKE:** Yes, that's correct.

**MRS OWENS:** And their waiting periods, which also apply to everybody.

**MS McKENZIE:** They can't actually give you some sort of differentially worse - - -

**MR LAKE:** No, but I think people around insurance and HIV - I think the exemption confuses people. I think people think insurance companies can really do what they like, if you've got HIV, and that's probably an education role for the insurance industry, I suppose.

**MS McKENZIE:** There is a concern though that's been raised in a number of

submissions, in the insurance exemption in the DDA, about - after you go through the bits about statistical and actuarial information, there's also this other catch-all which talks about rather relevant factors - you know, that it's reasonable to rely on. There is a concern that's been expressed in a number of submissions about that.

**MR LAKE:** Absolutely. I mean AFAO particularly was actively involved in the process up until I think about 98 - no, I think it was 96 - of trying to develop guidelines around insurance. That just stopped happening, and I think were really keen to get some clarification on that, because it is a bit of a catch-all. In our submission we've questioned - I suppose to be accurate about what the actual recommendation says, we've asked about - to review how effective the DDA has been in preventing discriminatory practices, and that there be support by the Commonwealth to meet with industry to represent that position.

The other issue is that it's an unknown, the level of discrimination in insurance, and whether that's actual perceived - I mean, if people self-select because they perceive they will experience discrimination, you get the same effect.

**MS McKENZIE:** Well, certainly for what it's worth, because a number of people from the Financial Services Association came and spoke to us, and they've also made a submission to us, and certainly they seem positive about memorandum of understanding. While recognising the difficulties, and that there's a lot of consultation involved, they certainly were positive about them.

**MR LAKE:** That's good to hear.

**MRS OWENS:** We asked them a question yesterday - we talked about the one with the Mental Health Council and we asked them the question, "What about using this model for other areas such as diabetes and HIV-AIDS?" and as Cate said, there was a reasonable response to that - I wouldn't say enthusiastic.

**MS McKENZIE:** Not, "We'll do one tomorrow" but - - -

**MRS OWENS:** But it was, "We'd be prepared to think about it."

**MS McKENZIE:** They're prepared to think about it, discuss.

**MR LAKE:** That's good to hear because when we heard about the mental health one we had scheduled some discussion about it. I suppose the difference with the mental health one was they were under a lot of pressure because of the things that had happened before that, that led up to that - were around antidepressants, I suppose there was a fair amount of pressure on them to do something about it.

**MRS OWENS:** But the other thing you should be aware of is in IFSA's submission to us they do say they feel the way they've been dealing with people with HIV-AIDS has actually improved over the last years, as they've got a better understanding of life expectancy and so on, and as more recent up-to-date data has come in showing the changes. Now, there is the question of how responsive and how quickly that works into their practices and into the practices of the underwriters. But it might be worth having a look at that.

**MR LAKE:** Absolutely, because one of the things is there's a much clearer marker of wellness and things that are almost definitive now, around viral loads and things like that, that weren't there before, and that was much more stabbing in the dark.

**MS McKENZIE:** Well, it may be that - apart from simply discussing the whole matter with them, there's the useful contribution that the association and the federation can make.

**MR LAKE:** Yes, absolutely.

**MRS OWENS:** Can I just ask you about your recommendation. You say, "The commission recommend a review of the effectiveness of the DDA in preventing discriminatory practices by the insurance industry," and so on. I guess we're already at review here, so it's a matter of whether you want more than what we'll be doing or whether you're happy for us to be thinking about this particular issue, or are you thinking about a separate review?

**MR LAKE:** I think this is a good process anyway, in terms of that it's an overall approach to the DDA. To be honest, I actually need to check back whether that - because it may be that that means that HREOC conduct a review of the effectiveness of - around insurance issues - - -

**MRS OWENS:** Yes, it could be - - -

**MR LAKE:** - - - than the Productivity Commission.

**MRS OWENS:** Like a systemic review by HREOC.

**MR LAKE:** Yes. That sort of feeds into what we've been trying to do around HREOC taking the lead, say, around an inquiry or something like that. The thing that's been significant and a lot of the changes that have come around through HREOC is their lead role; that carries a lot of authority, in the captioning, in the Building Code. In a lot of the processes that are in train I think HREOC really has a key role as the champion, and maybe is more successful in getting people to the table than, say, an organisation like ours might be - though notwithstanding what you've

just said about what the insurance industry said.

**MRS OWENS:** Well, from our point of view I think there's two issues. One is the exemption - you know, whether you have an exemption. We're looking at all the exemptions. Do you have an exemption? If so, what should it look like; what should the wording be? How open-ended should it be? That's one of the questions we asked IFSA yesterday. We said, "Have a think about that wording," because to me it looks quite open-ended and can it be pinned down in some way, if there is to be a change to the wording? What would it look like? So I really put that back into the court.

**MR LAKE:** That would be good for us to do as well. In the early parts of the negotiations with the industry, the concern was that it was a very very broad exemption, there was really poor quality actuarial evidence being used to justify some of their decisions, and that's changing now. I mean, they have got access to better information about disease progression, life spans, life expectancy, all of those sorts of things, that means you could actually constrain it a little bit more.

You could probably say the same for a lot of other illnesses, that it doesn't need to be as blanket as it was. I'm not sure about the intent of the exemption, whether it was one of those ones to give the industry time to get its science in order or something like that, to deal with it, or not. But I just question whether they need such a blanket exemption with the current state of research and medical knowledge.

**MRS OWENS:** So that is something that we'll be looking at further.

**MR LAKE:** So we'd probably like to maybe make some comments on that as well, subsequently.

**MS McKENZIE:** Is there any danger, do you think, that if HIV-AIDS goes off the front page - and that's probably the best way I can express it, I think - discrimination might rise, or people might forget what conduct it is that they're not supposed to be doing? Some years ago the treatments, precautions and nature of AIDS itself were considerably in the news in Australia. They still are, but not so much, I think. Do you think that poses a problem as far as the DDA is concerned? In other words, do you think people are likely - because it's no longer on the front page quite as much, are people likely to become less aware of their obligations?

**MR LAKE:** That's possibly true, because one of the other things is that there has not really been an ongoing process, and some of the cases, some of the - there probably has been - some of the national campaigns and things like that. In New South Wales over the last year there's been one of those "HIV doesn't discriminate - do you?" sort of campaigns been running, because I think there is a need to remind

people.

I'm currently working on a project about access for people with AIDS to community services. One of the things that comes up is that you actually need to be doing this fairly consistently, both through turnover of workforce but also just that people - because we're not talking about a lot of people, we're talking about 12,000 people across Australia, and so lots of people will never really meet a person with HIV or AIDS who will be open with them about that, and lots of service providers won't either.

The concern we have - because individual people almost have to redo the work themselves, and that might not be a huge case of discrimination but it's likely to have an impact on them and, as was noted here, it is continuing to happen, particularly around services - health services or community services and things like that. It's a bit hard to know what role HREOC and the DDA could have because, in a sense, organisations like AFAO and NAPWA, that's really their role to be highlighting these issues.

We face the same issue in the gay and lesbian communities about the lack of awareness meaning people aren't - well, there's the rise in transmission and there's a lot of - no-one really knows what that's about, but it's a concern. There's not the same sense of crisis that maybe informed people's behaviour before.

**MRS OWENS:** It was quite an interesting program - I think it was on last night's television, the 6.30 Report, and I think it was 10 years since that little girl Eve died - - -

**MR LAKE:** Right. Yes.

**MRS OWENS:** - - - and they interviewed the mother, and they made a quite interesting contrast between the treatment that she received as a little girl trying to go to kindergarten, and with the neighbours who built a big fence around their house, and talking about the sheer ignorance at that stage, compared with now where they featured a little boy who is HIV-positive and he just goes to the normal school, and until that point nobody in that community knew. They said, "As of last night they'll know," but he was totally integrated into the local community, living what appeared to be a normal life. The contrast was quite marked.

**MS McKENZIE:** Was there disclosure? When you say nobody knew, I wonder - - -

**MRS OWENS:** If they did know it didn't seem to be a factor, as far as I could see.

**MS McKENZIE:** It didn't trouble them.

**MRS OWENS:** It wasn't that clear, but it didn't seem to be a factor, unlike a decade ago when there was appalling treatment of that little - - -

**MR LAKE:** As I recall, I think part of the thing was that the kindergarten - it was like the authorities, "We'll have to tell the parents. We'll have to do all" - and that maybe those different sort of policies now are making - so that the school will be, "No, we don't - we just need to take these sort of precautions around infection"- like blood spill or anything like that but, apart from that, there will be no serious issues. Maybe the way the authorities are dealing with it is having an impact on that as well, which is good to hear, because I was thinking about the education but I hadn't heard of any of those sort of cases for a long time really around children being excluded from school or kindergarten and things.

**MRS OWENS:** It was just a very timely program that I saw.

**MR LAKE:** Yes.

**MRS OWENS:** Did you want to raise something else?

**MR LAKE:** I really wanted to, I suppose, highlight - I'm assuming that, and I notice that you've got a submission from ATSIIC but NAP or one of the member organisations of NAP was the Positive Indigenous Network, and I think probably if you go generally through HREOC stats and things, the access of Aboriginal people to HREOC and to the complaints system is pretty disastrous, and for Aboriginal-positive people it would be the same. We need to make sure that any of the strategies that they are doing are extended to people across the range of protections and issues that people face.

**MS McKENZIE:** I went to Alice Springs recently and had some visits with various organisations, some of indigenous people, some working with indigenous people, and that point was made very clearly by just about everybody I spoke to and there were long explanations of the numerous difficulties faced by Aboriginal people and also by in fact all those who live in remote communities having access to HREOC, knowing about the DDA, being able to have forms and a mode of accessing the complaints system which is culturally appropriate and so on. I entirely agree with you; it is really important.

**MR LAKE:** Thanks, yes, and also that issue of the practicality of taking action and what that means to people in those small communities and what other options there might be available to people that someone can act on their behalf that doesn't necessarily involve their disclosure and their sort of like identification and

stigmatisation in a community. I suppose I wanted to highlight for us, we're really pleased to see the progress on the various standards that are under way. As I said, for our purposes, the employment standard is the principal one that will make a difference.

**MRS OWENS:** Sorry, Rob. You said initially that when it was being developed you had some problems.

**MR LAKE:** At the last round it was sort of canned, really, and I think if there's discussion about a new model, it would need to be a new draft and things, but the actual existence of an employment standard, I think the principle of the standards is a valuable thing. For us, most people with HIV and AIDS don't need physical accommodations made. Most people, it's about work practices because so much of HIV and AIDS sufferers is episodic, and so it's about needing the flexibility of being able to work around that and maintain work. The family-friendly model is a great model for us, really.

**MRS OWENS:** So it's being able to have time off if there's sickness and be able to make it up at some other time; just greater flexibility.

**MR LAKE:** Absolutely, yes, and there are interesting models around use of banking of sick leave and things like that, and those sorts of ideas where workplaces sort of cooperate and support people who might, because of their illness, need to take more advantage of and things like that. There's some interesting quite creative models around flexibility and around chronic illness that I think aren't directly relevant to DDA but, in terms of standards and things, could be valuable.

**MRS OWENS:** What about using more mainstream methods like awards and so on to bring some of this into awards?

**MR LAKE:** Yes. There are good examples of enterprise agreements that have been where people just have had - again, I suppose it's like what they call a contingency, really. It's not like everybody gets eight weeks or 10 weeks' leave. It's just for a person who has a need of it, it's available to them, and people generally don't abuse those sorts of things. They take them as they need them. There are some good examples of that. Can I just - - -

**MRS OWENS:** Yes, by all means.

**MR LAKE:** The other thing, I suppose, is while it's not specifically around the DDA, I think some of our recommendations around useability of it come back to HREOC and resources to HREOC, and particularly I suppose the ability to do systemic work and to do policy work. There's the balance of resources between

complaints and policy and I suppose the ability of them to actually take up new issues and to engage with a number of issues is pretty constrained by the state of the resources at the moment in comparison to how it was when it was set up. There was a pretty major policy area in the early days, and I think we would really suggest that that be reviewed or revisited.

**MRS OWENS:** You also mentioned in your submission adequate resources for legal aid and community legal education, and other people have raised those possibilities with us.

**MR LAKE:** Absolutely. The DDLC - they have played a pretty significant role and they're a very small organisation these days. HALC, which is the HIV-AIDS Legal Centre, again, does really significant work in terms of identifying systemic issues, but also - what do they call it - the ongoing work with the broader legal centres and with the broader legal community around HIV, and that's an important issue too.

**MRS OWENS:** Does that legal service also take complaints through with people? Does it help people with their complaints?

**MR LAKE:** Yes. It's limited as to how many it can do and it really has to make - in the same way as the Disability Discrimination Legal Centres - they have to be really strategic about what they choose but they are able to take some through and they do a lot of referral and, as with some of the other services, try and, as much as possible, take advantage of pro bono where they can too.

**MRS OWENS:** Is that all that you have to raise with us?

**MR LAKE:** That's all from me, yes.

**MRS OWENS:** I think we've covered it.

**MS McKENZIE:** We've covered our questions, and we questioned you as you went along, which is the easiest way for us.

**MR LAKE:** Great.

**MRS OWENS:** Thank you, as I said, for the submission and for the little case studies that you've put into the submission. I may just have one question. Those case studies that you mentioned just before section 5, you've got "DDA claim to discrimination by associates of people with HIV".

**MR LAKE:** Yes.

**MRS OWENS:** Were they HREOC complaints or some other complaints?

**MR LAKE:** Yes, I think they would be HREOC complaints. They probably resolved under mediation, I think. Yes, it looks as though, from the reading of it, they wouldn't have gone to hearing. It looks as though they may have been resolved at mediation.

**MRS OWENS:** Okay. Thanks for clarifying that.

**MS McKENZIE:** That's tremendous.

**MR LAKE:** Thank you very much.

**MRS OWENS:** Thanks, Rob. We'll now break until our next participant arrives.

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**MRS OWENS:** The last participant today is the Marrickville Council. Welcome to our inquiry hearings. Could you please give your name and your position with the council for the transcript?

**MR REDMAYNE:** Glenn Redmayne, Marrickville Council's Community Worker, Disability Services.

**MRS OWENS:** Thank you, Glenn, for coming and thank you for the submission from the council which I presume that you had a hand in preparing.

**MR REDMAYNE:** Yes.

**MRS OWENS:** I might hand over to you to run through some key points for us.

**MR REDMAYNE:** Thank you. A few points that I'd just like to highlight - most of the issues obviously are within the submission but I thought if I just go through a few of these to indicate issues that are probably particularly relevant or I want to raise with the commission. The first one concerns, firstly, our support for the inclusion in the DDA of the ability to consider the intent to discriminate and I find that to be a particularly important aspect of the act. Although I have had a number of difficulties - not so much with the concept but applying it and determining an appropriate point to intervene in that process - particularly, I guess, I'd be looking at development approval, practices in councils; that's one of the major operations we would be involved in that has a particular impact on people with a disability.

There are a number of practices, I guess, where you could almost see a level of structural indirect discrimination. In relation to the act and how it covers the intent, you can clearly see that that could be something that will produce a discriminatory outcome but it's been very difficult to determine when it's appropriate for a local government authority to intervene in that, particularly given the way the act works and the fact that it's complaints based. The number of readings of it suggest that there isn't exactly a discriminatory experience up until somebody complains and then it triggers the engagement of the act in its provisions. So that's one point that's been particularly difficult to apply.

The second one relates to that and just concerns the complaints basis of the act. I'm assuming a lot of people have raised that throughout the structure so I won't deal with that too heavily, and a lot of that is within the submission already in the sense that a rights-based approach may be more appropriate in issues where discrimination is almost epidemic in proportions.

**MS McKENZIE:** So it would have duties. Is that really what you're on about?

**MR REDMAYNE:** Sorry?

**MS McKENZIE:** How would that approach be implemented?

**MR REDMAYNE:** A rights-based one?

**MS McKENZIE:** Yes.

**MR REDMAYNE:** I think the benefit in applying it in the local government context would be that what is required would be immediately obvious up-front. Things that could be assessed as being discriminatory - there would be a better mechanism to show where they would be and I would imagine that a range of practitioners would already be well versed in what they might be before it had got to a point of engaging a complaint. So I would see - again, if I can use a development assessment angle - a lot of that work would already be done through the architects, the designers, the people that are proposing a development, rather than it coming to the table and then having somebody assess it and say, "Well, it's likely that if this goes through as it is it will create an inequitable outcome for people."

**MRS OWENS:** Does this really imply having an Access to Premises Standard or are you talking about doing more than that?

**MR REDMAYNE:** I found that applying that sort of approach was much easier when all we were relying on was the advisory notes of HREOC at that point in time. So effectively there was, how I would have seen it, an appreciation of a rights-based method and the outcomes were stipulated, in a sense, in a sort of performance guide. It was then the responsibility of people involved in that practice to implement them in and about their professions, but there was something sort of measurable to do it. So I'm not necessarily saying that an Access to Premises Standard would or would not achieve that. I think there are other complications in having an Access to Premises Standard because it won't necessarily engage all the other factors that one looks at when looking at the pros and cons of a development. As I would see it, it would be a very functional thing about the constructed elements of the design of a building.

**MRS OWENS:** What are the other elements then? You've got these functional, structural elements - there are other elements that wouldn't get picked up like in the Building Code of Australia if that was standard?

**MR REDMAYNE:** There would be a lot of elements within the premises: the way that development is operated and its linkages to other aspects of the community, its proximity to transport and whether it's considered an appropriate development to go ahead, given the nature of that community or the sensitivities within it. They're all

issues that a council would make some level of assessment on through the planning regulations and controls within that. As I would see it, an Access to Premises Standard would be pretty well located because of its proximity to the Building Code of Australia as only being able to consider those real, detailed functional elements or specifications of dimensional qualities et cetera.

**MRS OWENS:** So there's something else that has to be covered that goes well beyond that?

**MR REDMAYNE:** Yes. I think one example would be the concept of an accessible pathway and thinking about - in an attempt to create what we would refer to as an accessible community - extending those pathways throughout the local area and giving people options for moving about and being included once they're in a place. So it's not just about can they actually functionally enter it and can they participate once they are inside and is it relevant and meaningful to them? From what I understand of the current proposed standard, I don't think that has the capacity to go into those things. I'm aware that there are other aspects of that standard that will be developed beyond its original introduction but I guess there are concerns there that, without all of those factors being in place at the one time, you'll get the very fragmented outcome.

**MRS OWENS:** I suppose you can't expect a standard to do it all and you may need to use other measures as well. You could have a standard and then complement it with other measures, which is really what the act is trying to do; it's a multi-functional approach, if you like, by having standards and action plans and the possibility of complaints and inquiries with HREOC so that, you know, there's a range of things you can bring together. You're not suggesting don't have a standard, are you, or are you?

**MR REDMAYNE:** I think a standard is useful. I've not seen what is being proposed so it's difficult to assess the impact of that, but I think the danger is many people believe a standard will solve all things and, as you've raised yourself, I think it's one component of a broader strategy to achieve the outcomes that the act attempts to reach. A concern I would have would be that in having a standard people might see that as being the resolution of all things and there would need to be a level of education that would be attached to that to alert people to the fact that there are still other just as important issues to be addressed; that's sort of step 1, I guess.

Another point that I'd like to highlight from the submission concerns the coordination with other agencies, including government, and we would encourage more of that. In our experience a lot of issues that we've attempted to address have been difficult because other agencies, other departments, et cetera - their progress towards their own action plans or their pursuit of equitable outcomes hasn't always

been in line with our own and there's a level of timetabling there that again, unless you've got a coordinated approach, it becomes difficult to achieve those outcomes in the same way.

I think an example there would be in the creation of some of the infrastructure measures that we've been involved in and the complications that have arisen out of utility services being located along those pathways that prevent you easily making them accessible, and having to enter into negotiations with them - I guess cold - would be the way that I'd explain it, in that there's no protocol in place necessarily that establishes that you need to work together in a certain fashion in order to achieve those outcomes with all of the parties involved. I think that's improved over the years but I think there's still some work that could be done to make that process smoother.

**MRS OWENS:** Is that sort of work something that you'd do through a Disability Discrimination Act or is it more setting up some sort of administrative or regulatory arrangement?

**MR REDMAYNE:** It could involve both, I would guess. I think there's a range of things that happen and engage local councils particularly - that there are already some levels of protocol involved with who will do what and who needs to be informed and who needs to get permission from one agency or structure before something can go ahead. I think that where access and particularly disability issues have been involved, there has not necessarily been the same level of understanding of the importance of that. I guess a protocol not dissimilar to the disability policy framework that we have in New South Wales could achieve those outcomes, as that was put together to be a whole-of-government approach. I would assume that many agencies that undertook that would have listed or identified a lot of those barriers and the coordination issues - that they need to make contact with other agencies and develop partnerships with. So I would see that as probably being a useful tool.

**MRS OWENS:** Thank you, that's interesting.

**MR REDMAYNE:** The other point that I'd like to raise concerns unjustifiable hardships and the inherent difficulties that those present, particularly for councils; they've had to really design their own practices around that in the absence of a lot of guidelines of how to approach that subject. The issue has been that because local councils are often in the forefront of dealing with issues with the built environment, the notion of unjustifiable hardship often comes up, again in the absence of a standard or in the absence of either the current Building Code or the existing Planning Act, to address that and give clear guidance as to how that should be addressed. That's made practice difficult in that councils have had to work out protocols to manage their own liabilities under the act to protect the rights of citizens

and local residents and also the interests of other stakeholders and business interests as well. So that's been a particularly difficult concept to try and get around and make some progress on. So I might leave that one just there.

**MS McKENZIE:** It is a matter that's been raised by numerous people. It is a difficult concept, though, because on the one hand you want it to apply to take into account individual circumstances. On the other hand, if you do make it apply to take into account individual circumstances, it's almost - simply because of that - impossible to express general rules that will predict with certainty its application in particular cases.

**MR REDMAYNE:** Yes.

**MS McKENZIE:** It's very difficult.

**MR REDMAYNE:** In New South Wales, particularly, there's a little bit of pressure experienced to try and increase the efficiency of particularly development approval practices and the speed under which they go through, and trying to make a comprehensive assessment of unjustifiable hardship on a case-by-case basis which - as you acknowledge, you really need to do it on a case-by-case basis. That can create difficulties and slow down the process unless you've got adequate instruments to try and navigate that a little.

I'm not sure how the standard might relate to that and particularly how it would relate to existing buildings, which is one that is mostly the cause of the difficulties with measuring unjustifiable hardship. I think over the last few years there's been an appreciation that the concept of unjustifiable hardship isn't necessarily as appropriate to apply to completely new concepts of developments or proposals, which I think has been a positive move.

**MRS OWENS:** While we're talking about existing buildings, what have you done about your own heritage buildings? Have you had to deal with issues of access to heritage buildings?

**MR REDMAYNE:** Yes, probably predominantly in our own town halls and community centres. In general terms I think the approach that we've taken is that while we're certainly respectful of heritage and it's a part of Marrickville and the look and what makes people enjoy the aspects of living in Marrickville, we also recognise that there's a need for everybody to be able to participate and enjoy those aspects and the buildings and the quality and what goes on within them, so we've really tried to ensure that we meet both outcomes. I've not found that there's been particularly difficult resolutions to achieve that.

I think they've been easy, providing you can get people to appreciate that you need to achieve both outcomes and that you can still maintain the heritage qualities of a building while ensuring that it remains functional and relevant to a contemporary society. I think there are existing protocols that are out there that actually guide people in the priorities in determining when a heritage feature needs to be maintained or, if it can't be, what application you would use to ensure people with disabilities' needs are achieved in the same context. I think often that's been raised as a particular difficulty. But I've not seen too many instances where it's actually unachievable. It's just a question of educating people as to what the outcomes need to be and you're trying to achieve a situation in which everybody gets an opportunity to appreciate the heritage character.

**MRS OWENS:** I don't know whether that same attitude applies to all councils. I've had the experience of going to Wangaratta in Victoria where I think the council chambers is inaccessible and I don't know whether anything is going to be done about that.

**MS McKENZIE:** Certainly Leichhardt Council, who made a submission to us, takes a similar view to Marrickville.

**MR REDMAYNE:** I guess the priority that we've tried to impart is that public buildings need to be as accessible as we can achieve them. Sometimes that's not always to the degree of contemporary standards in terms of AS1428. However, I think we've pretty much achieved that in most instances or been able to achieve it by staging the development over time but ensuring that the most public aspects of the building or its purpose - and particularly buildings such as council chambers, libraries, et cetera - are created or improved so that everybody can utilise them freely. That's been a bit of a priority.

**MRS OWENS:** Has it been costly for the council, or for the ratepayers, I should say?

**MR REDMAYNE:** I think when you've got an area in which the built character is so old, there's an appreciation that the maintenance costs of that are quite high anyway and that if what you're trying to achieve is the most efficient use of that building while maintaining its heritage character and quality, there's a sense that that will involve a certain level of maintenance and a higher cost perhaps than otherwise over time and certainly I guess older buildings get to require more maintenance quicker than what newer ones do.

**MS McKENZIE:** So this is actually getting back - and it's a very broad meaning - of maintaining accessibility as well as heritage character.

**MR REDMAYNE:** Yes.

**MRS OWENS:** It's a good way to avoid any community backlash saying, "Our rates are so high because you're doing these special things for particular groups." Maybe you wouldn't have that community backlash in Marrickville but it's always a possibility. People don't like paying higher rates. Each year when they go up there tends to be a bit of - you know, people do complain and say, "What are we getting for our money?"

**MR REDMAYNE:** Yes.

**MS McKENZIE:** If they can see greater accessibility as distinct from a bottomless pit, obviously I would have thought their complaints might be less.

**MR REDMAYNE:** Yes. I think it's also about educating the community that the benefits will be spread beyond just the person with the disability, but also to their family, to their friends, to the rest of the community, to families. I guess we're lucky in Marrickville and that one of the things we really pride is our appreciation of diversity and that's a very practical way that we can demonstrate that.

Another point is in regard to standards and particularly the consultation processes that have been a part of their development to date. I'd just like to raise a view that I think local government has probably not been as effectively consulted to date as what could have been possible and that I feel this is a little unfortunate, given its front-line position and given that local government is, as I've mentioned before, probably the first agency that is able to remove many of the barriers to people with a disability in the community; and would suggest that probably they need to be engaged a little more strongly in the future in the development of them.

Another point is that I think that continual attention needs to be made to educating the community understanding of disability and how it affects those that are currently living with a disability or may live with a disability in the future; and that access issues, disability issues, disability discrimination issues in the DDA is not a minor point but it's something that actually involves everybody in the community and will at some point and that everybody has a responsibility and a role in reducing that discrimination. If that's engaged, the community as a whole will benefit from it, and it's not just a sidelined or separate issue.

I think that's a message that's been increasing over the years but we'd encourage a bit more work towards that because I think that can be forgotten without continual reinforcement. I think the results of doing that are that the more complex aspects of removing barriers become easier once the community understands where you're going or what your perspective is and what you're trying to achieve and that

you're trying to be more inclusive and that will eventually aid their quality of life as well.

I guess the last dot point I'd like to make is about some of the positives particularly that we've experienced with the DDA. It's been particularly successful in putting the issues on the agenda of many people and many agencies which I don't think was around as completely prior to its introduction. It's now a topic that people talk about and it's one that increasingly professionals deal with and I think that's been a very positive outcome of having the act. It's also raised the bar about what should be expected, both from the general community and from people with a disability and broadly what is required for a society to be inclusive and for its citizen to reach their potential and be able to participate in all that goes on within their local area. So in those two points alone, I think the DDA has achieved much. That's all the highlights that I'd like to make at this point.

**MRS OWENS:** That was great.

**MS McKENZIE:** That's really helpful.

**MRS OWENS:** While we're talking about putting the issue on the agenda for agencies, was your own job or the job of community worker, disability services at the Marrickville Council there a decade ago?

**MR REDMAYNE:** No.

**MRS OWENS:** So what brought that job about? Was it the act or just greater recognition of these issues? How did we get to have a community worker, disability services?

**MR REDMAYNE:** From my perspective, I think the act was instrumental in that because it raised the issue and put it on the local government agenda. There would have been people within local government working on those sorts of issues at the time but the requirement to focus on them a little more heavily was probably increasing. I think the community became better at raising issues and advocating for things to happen, which required more resources to be targeted towards that area. I think at the time when my position was created there was more of an emphasis of change and focusing on disability issues. Not to say that that's not necessarily the case now, but that was certainly the turning point I think and it enabled people to focus on putting resources into an area to get an outcome in regard to disability discrimination and the needs of the community.

**MS McKENZIE:** But other councils don't have a disability officer or a position like that.

**MR REDMAYNE:** Some councils do. A number of councils in the Southern Sydney region of councils have a community worker with a portfolio of disability issues specific, but there are not many of us. I think there are about three, maybe four. Many of the positions are aged/disability services workers and are funded or partially funded through the HACC program. I think often it's easier to focus on these issues if that's your only focus, as opposed to concentrating on them along with aged services issues, because I think there are differences in that.

**MRS OWENS:** So would you say that it's the more enlightened councils that have focused on disability issues?

**MR REDMAYNE:** It's hard to say, only being from one council, I guess; but I think councils that have a real interest in their community and that have a particular commitment to social justice principles, they're the ones that probably see the benefits in having either a person specifically dealing with those issues or of having some approach in place that will mainstream those practices throughout the organisation but certainly maintain it as a focal point, yes.

**MS McKENZIE:** You have an action plan?

**MR REDMAYNE:** Yes.

**MS McKENZIE:** Have you got any comment about the process of developing it?

**MR REDMAYNE:** I think the development of an action plan is a very important component in one gaining a relationship with the community that you're addressing to remove the barriers for. It also serves as a good tool to educate the community broadly and also the organisation into what's required; what's currently happening, or the way the community perceives the issues, and it gives people an emphasis on how to work together to remove them, so I think the process of developing an action plan in many ways is certainly as important as the target at the end of it or the strategies that are developed.

**MS McKENZIE:** Because it sort of leads to awareness.

**MR REDMAYNE:** Yes, awareness and skills people up into identifying the issues and addressing them. One of the things that happened I think with Marrickville is that when we did the DDA access action plan and had the consultations for that it enabled a lot of the staff at the time to actually engage with the local community of people with a disability and opportunities to do that prior probably hadn't been as obvious, and I think the relationships that were formed there through that process were really important in setting the tone of how those issues would be addressed later

on. I guess the trust that was formulated in those days was really important. I think there can be a danger if you have an action plan developed sort of off site to some degree because I think sometimes it's not necessarily owned by the organisation.

**MRS OWENS:** When you say "off site" do you mean just get somebody - a consultant - in or something to do it or have somebody else do one that is going to cover your council, so somebody doing it - - -

**MS McKENZIE:** A generic type.

**MRS OWENS:** A generic action plan.

**MR REDMAYNE:** Yes. I think there are models for like generic action plans that - the structure of them isn't that bad. It can actually work quite well. It's just that it's the process in understanding why you're putting those issues in the box and what they mean and who they relate to that is best achieved by doing in-house and with the community involved because, without that, it is difficult then to establish the trust and the communication that is a part of negotiating a strategy. It might not always be a strategy that is obvious but it might be one that that particular community is prepared to go with or work alongside people to develop a partnership to complete, so I think that is probably the most important thing I have found about the action plans, and recognition that they're a living document and that their purpose should be to inform and advise other planning processes within a council.

**MRS OWENS:** So you could use that document in terms of dealing with your colleagues who are engineers or who are ticking off applications, building applications, and so on.

**MR REDMAYNE:** Yes. There's a range of strategies in our own that require or that mean you must work together, cooperatively, in order to achieve a particular outcome and remove a particular barrier. I think it's easier because both parties are then aware of what you're trying to achieve and why, and it also recognises that each professional has a different range of skills that are equally important in arriving at the solution, and it gives you a structure to do that, which I guess you can still do without that, but it's not as easy.

**MRS OWENS:** You said your action plan is a living document, so you update it - you monitor it?

**MR REDMAYNE:** Yes. We do that through a range of reporting mechanisms and link it particularly to strategies in our management plan and in our social plan. In the last few years it has been linked more strongly to council's social plan as an exercise in mainstreaming those issues, and a number of the strategies have probably

developed a bit of a life of their own in that they're distinct projects that are ongoing and people recognise the benefits of them.

**MS McKENZIE:** Can you give us an example?

**MR REDMAYNE:** I think the strongest example is probably our Accessible Pathways Program and our Pedestrian Access and Mobility Plan. Both of those relate to the introduction of accessible facilities in our infrastructure, so it involves our engineering department and, to some degree, our planning department, and our community development department, and our access committee and, through that, our residents. I think that has been a good example of a cooperative approach where people are consulted and plan for a more holistic approach to achieving access than just responding to individual requirements.

That program has been operating for a number of years now and is revisited every year, looked at and improved, and we have got to the point where we're able now to include other aspects of accessibility within it, and started to formulate the links between the infrastructure, planning for accessible and/or adaptable housing, where services are located, where accessible parking is, where our parks and reserves and recreation centres are - or programs from them will run - so it starts to generate a very holistic way of looking at the area and how people work and live within it.

**MRS OWENS:** Just while we're talking action plans, you said in your submission on page 9 that the disability policy framework adopted by the New South Wales government required state departments and agencies to develop - what you have put in inverted commas - "disability action plans". Would your council have done your disability action plan if it hadn't been required by state government? Would it have done it voluntarily?

**MR REDMAYNE:** It was done voluntarily. Our action plan was a Disability Discrimination Act action plan and we actually started that process and pretty much had completed it prior to - - -

**MS McKENZIE:** The direction.

**MR REDMAYNE:** Sorry?

**MS McKENZIE:** Prior to the policy of the - - -

**MR REDMAYNE:** Yes, prior to the DPF. At about that point I understand there were negotiations going on to ensure that developing a disability policy framework action plan was very similar to developing a DDA action plan, so given that we had already started that process and were going to achieve the same thing, it was sort of

like not necessarily relevant to have two that were the same.

**MRS OWENS:** I think we have just about covered everything. The only other thing is that you did note in your submission that there is a shortage of appropriate and affordable housing for people with disabilities and that that's not covered by the DDA. We are wondering about this issue. Is it a Building Codes issue or is it a DDA issue? How do we deal with housing?

**MR REDMAYNE:** It is certainly a big issue and it is one that has gained increasing attention over recent years. I think there is work that's going on now that I am aware of to incorporate - adapt - some level of adaptability within housing in the Building Code, although what tends to happen in New South Wales in regard to housing is that it is largely a domain of the planning framework and having some encouragement for adaptable - or some level of adaptability - in housing within that framework would, I think, possibly achieve similar outcomes or quicker outcomes.

It's hard to say what the best method of that is, other than I think more attention needs to be paid to it. A number of local councils, through that structure, have developed DCPs - or development control plans - which stipulate the requirements for a range of things, and this is one example where you could have provisions for adaptable housing within those local codes that is attached to the Building Code, but not necessarily driven by it. Marrickville has a development control plan on access and mobility and, within that, we have provisions for adaptable housing and, through doing that, we have achieved quite a number of new units within the area just over the last two to three years - the increase has been quite marked - so I would suggest that that is probably also a viable way to improve the stock, certainly of new housing, so there are more opportunities for people than perhaps waiting for other initiatives to incorporate it, as well.

**MRS OWENS:** So again a multi approach to it.

**MR REDMAYNE:** Yes.

**MRS OWENS:** Glenn, is there anything else you wanted to raise with us?

**MR REDMAYNE:** I can't think of anything now, no.

**MS McKENZIE:** It was a really interesting submission and the points you have highlighted are really helpful to us, also.

**MRS OWENS:** You have done it in a very, very clear way, I have to say.

**MS McKENZIE:** Yes.

**MR REDMAYNE:** I'm glad of that - that was the attempt.

**MRS OWENS:** Does your colleague want to come up and say anything more? No? Thank you for that.

**MS McKENZIE:** Thank you very much.

**MRS OWENS:** I'll just close off for today. That concludes our proceedings in Sydney. Thank you for coming today.

**MR REDMAYNE:** Thank you.

**MRS OWENS:** I adjourn the proceedings and we will resume our hearings in Melbourne on Tuesday, 22 July at 9.30 am. Thank you.

AT 3.08 PM THE INQUIRY WAS ADJOURNED UNTIL  
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